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**Childhood Resilience in Relation to the Physical and Mental
Health of the Family**

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Declaration

The contents of this thesis have not been submitted for a degree at any other university. It is entirely the candidate's own work and contains no material based on any collaborative research. The author developed the research ideas and design, and carried out all data collection and analyses, with supervision from Dr Eve Knight, Coventry University, and Dr Sarah Kent, Dudley and Walsall Mental Health Partnership NHS Trust. Participant recruitment was supported by Finham Park School, Coventry, by Dr Heather Stirling and her colleagues, University Hospital Coventry, and by Dr Melanie Kershaw and her colleagues, George Elliot Hospital, Nuneaton.

Thesis Synopsis

The thesis comprises three papers; a literature review, an empirical paper, and a reflective paper. The first is a critical review of studies of interventions aimed at preventing depression among children of parents with depression. Much research evidences the potential negative impact on this young population, and therefore researchers have begun to use family, cognitive-behavioural, and parenting interventions, to try to prevent the onset of depression in these children, instead bolstering resilience. The review finds that although the research is relatively new, there are promising signs that all of these types of interventions may help in some way towards preventing the transmission of depression from parent to child, but further research is needed to determine the validity and duration of these effects.

The empirical paper presents a study of resilience in children who have a sibling with diabetes, as compared to a control group. It was found that when controlling for covariates of self-esteem and family functioning, resilience levels were the same for both groups. Previous research has focussed on the potential negative impact on siblings of children with health or learning difficulties, but this research suggests that this population may also be as resilient as their peers whose siblings do not have such difficulties.

The final chapter discusses reflections on the research process, and areas of personal and professional learning and development that have arisen as a result.

Chapter 1: Literature Review

Preventative Interventions for Children of Parents with Depression: A Critical Review

Chapter word count (excluding tables, footnotes and references): 7943

Paper drafted for submission to Clinical Child Psychology and Psychiatry.

1. Abstract

Research suggests that children living with a parent with mental ill health are at risk of developing emotional and behavioural difficulties, and mental health problems (Jaffee & Poulton, 2006). However, some research also highlights that not all children develop these difficulties, with some developing more positive attributes (Mordoch & Hall, 2008). In the field of parental depression, theories have been developed which attempt to explain the apparent transmission of symptoms from parent to child, including moderating and mediating factors that may help prevent such transmission. Using these theories, researchers have begun to develop interventions which aim to prevent the potential negative impact on these young people, instead bolstering their resilience. Fifteen studies are critically reviewed, each of which attempts to offer such an intervention to families experiencing parental depression. Although this research is in its early stages, it provides a useful foundation from which to develop targeted interventions to those families most in need of support. Preventative interventions are not common in health settings, but it is argued that both the long-term psychological and cost benefits could outweigh the initial expenditure. Areas for future research are discussed.

2. Introduction

2.1. Parental Mental Health and the Impact on Children

Mental health difficulties are common, with some twelve-month prevalence estimates as high as 27% of the adult population (National Centre for Social Research, 2009; Wittchen & Jacobi, 2005). It therefore follows that many parents will experience mental ill health, with estimates suggesting that up to half of all mental health service users are parents (Göpfert, Webster, & Seeman, 1996; Leschied, Chiodo, Whitehead, & Hurley, 2005).

Researchers studying the impact on children of having a parent with a mental health difficulty report mixed results. Some studies suggest there may be no increased risk of emotional or behavioural difficulties in offspring (Mannuzza et al., 2002; Van Beek, Perna, Schruers, Muris, & Griez, 2005), with some suggesting potentially positive outcomes such as increased problem-solving and sensitivity to others (Mordoch & Hall, 2008), improved bonds between parents and children (Aldridge, 2006), and greater understanding and tolerance of mental health issues (Cogan, Riddell, & Mayes, 2005).

Whilst the overall picture appears mixed, however, most researchers agree that alongside any potential positive outcomes, all of these children are likely to experience some adverse effects due to combinations of genetic and environmental factors (Jaffee & Poulton, 2006). Much research has indicated

at least some negative consequences for young people living with a parent with mental ill health, such as elevated anxiety, depression or behavioural problems (Gladstone, Boydell, & McKeever, 2006; Hanson et al., 2006; Leverton, 2003; Micco et al., 2009; Mordoch & Hall, 2002; Ostler et al., 2007; Smith, 2004; Somers, 2007). It has been suggested, however, that the negative impact on children's emotional and behavioural outcomes can be moderated by factors such as self-esteem (Abela & Skitch, 2007) and parent and child gender (e.g., Cortes, Fleming, Catalano, & Brown, 2006; Landman-Peeters et al., 2008; Ohannessian et al., 2005).

2.1.1. The impact of parental depression on children.

Within the field of parental mental health research, there is a growing literature focussed on children of parents with depression (see reviews by Gotlib & Lee, 1990; Hammen, 2009). As above, there are mixed findings, with some authors reporting the potential for both positive and negative consequences for these young people. For example, Abela and Skitch (2007) found that children of parents with depression were more likely to have elevated levels of depressive symptoms following a rise in stressors only if they had low self-esteem and high levels of dysfunctional attitudes. Coping ability has also been found to have a moderating effect (Jaser et al., 2008). Similar mixed results have been found for children whose parents do not necessarily meet full DSM-IV criteria for major depressive disorder but who report elevated levels of distress (Papp, Cummings, & Goeke-Morey, 2005; Powdthavee & Vignoles, 2008).

Further, specific effects of gender have been found with regard to depression in parents and children, with maternal depression being more likely than paternal depression to correspond to depression or behavioural difficulties in children (Tully, Iacono, & McGue, 2008), yet paternal depression nevertheless affecting fathers' parenting behaviours, and therefore potentially children's emotional and behavioural outcomes (Wilson & Durbin, 2010).

2.1.2. Mechanisms of transmission of depression.

Several authors have outlined theories attempting to explain how depressive symptoms may be transmitted from parents to children, including factors mediating this transmission as well as moderating factors that may either further enhance or help to prevent transmission. There exist two main groups of theory, the first being integrative and highly complex, considering how various factors may interact in a dynamic, multi-directional manner. For the purposes of this review they will be referred to as, "Integrative Theories". The second group of theories (referred to hereafter as "Discrete Theories") are less complex in considering only one of the possible factors and focussing on building the theory around this factor alone, whilst acknowledging the wider interplay of other likely variables. These narrower theories are perhaps of more practical use, helping clinicians to find a distinct focus for family interventions with the intention of preventing transmission of symptoms from parents to children (Smith, 2004).

Indeed, it is essential for clinicians to ground such preventative interventions in theory, in order that they are safe and effective (James, Fraser, & Talbot, 2007), and the interventions reviewed later in this chapter will be organised by which group of theories they are based upon.

2.1.2.1. Group 1: Integrative theories.

Two groups of authors have attempted to combine biological, psychological, social, and environmental variables within a developmental framework, to explain how the transmission of depression may be mediated from parents to children, as well as considering factors that could moderate this transmission (Beardslee, Versage, Salt, & Wright, 1999; Goodman & Gotlib, 1999). The Beardslee et al. (1999) model was developed as part of a longer-term research strategy with ongoing evaluation of a preventative intervention, discussed within the review below. It focuses largely on variables that can be manipulated through such an intervention, such as self-understanding, attention-giving, and problem-solving.

Perhaps the most integrative of these models is that of Goodman and Gotlib (1999), expanded by Goodman (2007), Goodman and Brand (2008), Goodman and Tully (2008) and Joorman, Eugène, and Gotlib (2009). This theory was developed specifically for the explanation of transmission of maternal depression to children. Grounded in empirical evidence, it purports four possible factors (“heritability of depression”, “innate dysfunctional neuroregulatory mechanisms”, “exposure to negative maternal cognitions,

behaviours and affect”, and “the stressful context of the children’s lives”) mediating the transmission of depression from mother to child, with an awareness that all four may be interlinked, but may not all be present in each case. All except the second factor could also be used to explain the transmission of paternal depression (Ingram, 1990; Kowalik & Gotlib, 1987; Levinson, 2009; Sullivan, Neale, & Kendler, 2000).

In addition to these mediating factors, the authors purport three moderating factors (father’s health and involvement with the child, the course and timing of the mother’s depression, and the child’s own characteristics). Again, these factors could equally apply in families affected by paternal rather than maternal depression.

2.1.2.2. Group 2: Discrete theories.

The two main approaches in this category focus on either child (predominantly cognitive) or parent (parenting) factors. Although these factors are the same as those discussed within the integrative theories above, these authors discuss each factor individually, with a specific focus on one possible mechanism of transmission, although usually with an acknowledgement of the wider context that each is embedded within.

The child-focussed theories are based on the cognitive literature of depression (Abramson, Seligman, & Teasdale, 1978; Beck, 1967), which suggests that a vulnerability towards negative, self-critical thinking styles can

render a person depressed in response to a stress trigger, and that such cognitive styles then serve to maintain this depression. The child-focussed theories of transmission therefore relate to the child's vulnerability to negative cognitions (Garber & Martin, 2002). This vulnerability is attributed to both environmental factors such as stressful life events (Garber & Martin, 2002) and biological factors, considering the impact of the parent's genotype and phenotype on the child (Nantel-Vivier & Pihl, 2008).

The parent-focussed theories denote parenting as a mechanism of transmission. Authors discuss research showing that both mothers (Riley et al., 2009) and fathers (Wilson & Durbin, 2010) with depression demonstrate fewer positive parenting practices such as warmth and praise, and more frequent use of negative parenting such as punishment (Vostanis et al., 2006), as well as less involvement with, and poorer supervision of, the child (Smith, 2004). It is thought that factors such as lowered thresholds for irritability and more life stress may mediate this relationship between depression and parenting practices (Smith, 2004).

2.2. Preventative Interventions with Families Experiencing Parental Depression

Each of these models indicates where to intervene with families to promote the best possible outcomes among children. Interventions should therefore be grounded in these theoretical models (Goodman & Gotlib, 1999; James et al., 2007) and targeted before symptoms become apparent in the child if

prevention is to occur (Smith, 2004). Indeed, there is growing interest in prevention research and practice within the field of parental mental health, with several presenting problems being targeted in this way, including anxiety, psychosis and addictions (see reviews by Fraser, James, Anderson, Lloyd, & Judd, 2006; James et al., 2007).

3. Aims of Review

Given the proposed mechanisms of transmission of depression (Beardslee et al., 1999; Garber & Martin, 2002; Goodman & Gotlib, 1999; Smith, 2004), as well as the growth of prevention research and practice, it may be important to develop family- or child-based interventions alongside adult mental health services. Whereas previous reviews have compared such interventions across a range of presenting mental health problems (Fraser et al., 2006; James et al., 2007), this review will have a narrower focus concentrated on critically evaluating interventions for families with parental depression. It is hoped that this may be especially clinically relevant given that depression is one of the most commonly reported mental health problems (National Centre for Social Research, 2009), and that large amounts of government funding have been assigned to provide therapeutic interventions specifically for depression and anxiety (Department of Health [DoH], 2008).

Therefore, in order to make recommendations for clinical practice, the current paper will aim to:

- Review the ways in which children and families have been involved in interventions when a parent has depression
- Critically evaluate whether such interventions may prevent mental ill health, and improve well-being, in children
- Identify areas that should be promoted within clinical practice
- Discuss areas for future research

4. Search Strategy

The databases Psychinfo, Medline, ScienceDirect and Assia were searched to identify appropriate papers. Four groups of search terms were used. These were Intervention, Therap*, Treatment, Cognitive, Behavio*, CBT, Program*, Promot*, Prevent*, which were all cross-referenced with the terms Mental, Psych*, Emotion*, Mood, Affect, Depress*, Distress, and Parent*, Maternal, Mother, Paternal, Father, Famil*, and Child*, Daughter*, Son*, Young, Offspring, Young carer*, Youth. Reference lists of all appropriate articles were then searched individually for additional relevant papers.

4.1. Inclusion Criteria

Research studies which described and evaluated an intervention for parents, family, or children where a parent in the family has a primary diagnosis of depression, were included. These included new and follow-up studies,

randomized trials and pilot studies. Papers which were peer-reviewed and published from 2000 onwards were included in this review. Older papers which were directly related to newer, follow-up papers, were also included.

4.2. Exclusion Criteria

Studies reporting an intervention where the parent(s) had a primary diagnosis other than depression were excluded. Unpublished studies, dissertation abstracts and non-English language papers were excluded. Papers reporting intervention for families with very young children, including post-natal depression, were excluded. This is because post-natal depression is considered as a classification of depression in its own right due to the separate research interest it has attracted, and the particular importance of the mother-child relationship and attachment (Oates, 2003). This review focuses therefore on older children who could be actively involved in an intervention¹.

The original literature search resulted in a total of 70 papers, which, after sorting for inclusion and exclusion criteria, resulted in 22 suitable papers. However, five of these 22 papers were follow-up studies from another paper in the review and two offer further analysis of previously collected data. Therefore 15 original studies across 22 papers are included in this review.

¹ See Boyd & Gillham (2009) and Gladstone & Beardslee (2002) for reviews of interventions targeting children from infancy

5. Review of Studies

The 15 studies are split according to the theoretical background of the intervention, whether implied or explicitly stated. The first ten studies (across 17 papers) are those using an integrative intervention targeting several parent, child, and environmental factors, as related to the integrative theories of depression transmission. The remaining five studies are those with a narrower focus using the discrete theories of either child (cognitive) or parent (parenting) factors as the mechanism of transmission. Tables 1 and 2 (at the end of the chapter) show a summary of the studies.

5.1. Review of Studies Using an Integrative Theoretical Foundation

The ten studies in this section include seven studies using fundamentally the same design (the Beardslee design) which will be described first. Of these seven, the first three studies (analysed and followed up across seven papers) describe the bulk of Beardslee's research in this field to date. The following four studies (across five papers) also use the same essential Beardslee design but adapted to particular populations.

The final three studies (across five papers) describe three differently designed studies which also use an integrative theoretical foundation to prevent transmission of depression to children.

5.1.1. The Beardslee design.

The Beardslee design (Beardslee et al., 1999) uses a randomized trial of a clinician-based intervention compared with didactic lectures for parents, with both interventions having the same aim of using psychoeducation to improve family understanding of depression, preventing potential transmission. The interventions are also intended to improve resiliency, problem-solving skills, and parental focus on the children. The clinician-based intervention has the benefit of each family being able to discuss concerns with their clinician, as parents meet alone with a clinician for up to ten sessions. The child also meets the clinician once, and the same clinician then facilitates a family meeting. Long-term follow-up is provided to families in this condition.

Families in the lecture condition have no direct child contact with a clinician, instead receiving two lectures directed at a group of parents, followed by opportunities for questions and group discussion.

Both interventions are aimed at families with children aged 8 to 15 years.

The rationale is that this is the age that children start to have higher risk for developing depression and is also when they develop the capacity to understand depression and related factors. It could be argued that 8 to 15 years is too large an age range, and that by the age of 15 many children will already have passed the age when prevention work could be most effective. Nevertheless, this allows for more families to be included in a potentially strength-building intervention.

Beardslee et al. (1993) describe a pilot study of this design. Parents in both conditions reported decreased worry and increased knowledge of depression and risk and resilience in children. Parents in the clinician-based group, however, reported more attitude and behaviour changes in themselves, more change in family communication, more mutual understanding with spouse and children, and more strategies to deal with depression than parents in the lecture condition. However, the results are difficult to interpret due to the small numbers in each group (12 families in the clinician-based group and 8 in the lecture group), the different numbers of families in each group, and the lack of effect-size reporting. Only significance (p) values are reported. Further, there are no child outcome measures, despite the aim being to improve child well-being.

In a larger study of 37 families, Beardslee, Versage, et al. (1997) measured child mood and behaviour before the intervention, but unfortunately did not repeat these measures following the intervention, instead reporting only parent and family changes such as improved communication and understanding, as reported by the parents. The larger number of participants in this study is positive, however, validating their finding of more positive change in the clinician-based families as compared to the lecture families.

Follow-up studies (Beardslee, Wright, Clarke-Rothberg, Salt, & Versage, 1996; Beardslee, Wright, et al., 1997) suggested positive outcomes in the longer-term following both interventions, but with the clinician-based intervention still providing stronger results. Beardslee et al. (1996; 3 year

follow-up) again only report parent outcome data, but Beardslee, Wright et al. (1997; 1.5 year follow-up) deliver a thorough set of data including child self-report, which they state was also collected pre-intervention. It is unfortunate that this pre-intervention data was not described previously, but a strength of this paper is that it incorporates parent and child data for the first time, in line with the theoretical foundation of the interventions. However, it is hard to consider the lecture group as a strict comparison group, since some parents saw only a video if they could not attend the lectures. They will therefore have missed the group discussion, and consequently their results may have exaggerated the overall difference between the two groups. A further criticism of these studies, is that it is unclear exactly when, how and how many participants were recruited, and which families were followed-up. Therefore, although the reported retention rates in these two follow-up papers appear to be good, it is difficult to follow the recruitment and retention procedures with much clarity, and therefore bias in follow-up data due to issues such as loss of participants and the opt-in procedure cannot be ruled out.

Focht-Birkerts and Beardslee (2000) described 6-year follow-up qualitative data from three adolescents who took part in the clinician-based intervention, with a focus on family and affect communication. The authors concluded that over time, the adolescents developed more openness to talk about their reactions to their parents' depression, and that this aided their levels of resilience, as well as solidifying the relationship they had with their parents. Although the authors acknowledge that this development may be in part due

to their “increasing maturity and cognitive ability” (Focht-Birkerts & Beardslee, 2000, p. 433) over the six years they were followed, they also suggest that the intervention, and having regular opportunity to talk to the researchers at follow-up interviews, helped these adolescents to talk more freely. Focht-Birkerts and Beardslee do not, however, offer any lecture group comparison children, and the small number of participants in this report (N=3) significantly limits their conclusions. It is a rather process-driven report and offers no qualitative analysis, therefore adding little evidence for the long-term efficacy of the intervention.

Some of Focht-Birkerts and Beardslee’s (2000) conclusions are supported, however, by long-term follow-up of over 90 families, by Beardslee, Gladstone, Wright, and Cooper (2003; 1-year and 2.5-year follow up), and Beardslee, Wright, Gladstone, and Forbes (2007; 4.5 year follow-up). These studies found that both interventions were helpful in changing parents’ child-related behaviours and attitudes, and child-reported understanding of parental depression, but that these effects were increasingly stronger in the clinician-based intervention over time. Family functioning and children’s internalising symptoms improved in both groups equally. The large sample sizes and excellent participant retention rates in these reports render the strong effect sizes credible, and start to indicate reliable positive outcomes over time. Starting to measure children’s self-reported symptoms over the long-term is also a positive step and important given the preventative focus of the interventions.

5.1.2. Studies using an adapted Beardslee design.

Butler, Budman, and Beardslee (2000) adapted the psychoeducation components of Beardslee's design, to produce a child video and a parent video and manual, for families unable or reluctant to attend regular sessions outside the home. The study was a randomized controlled trial (RCT; N=74 families) with a waiting list control group. Unfortunately, the authors do not justify the age range (7 to 12 years), which is different to the original Beardslee design, and expects children at different developmental stages to understand the same material. Sadly, no child self-report data was collected, either about the usefulness or understanding of the video, or of depressive symptoms or functioning. Parent-reports suggested that the videotape intervention improved children's functioning, improved spouse-support, and improved the family's ability to talk openly about depression, when compared with the control group. Although such a video intervention perhaps makes intuitively good clinical sense, it needs further data collection and analysis. It also requires more integration between child and parent intervention if it is to utilise thoroughly the integrative model to prevent depression transmission. This could perhaps be achieved through the use of a facilitated family meeting as in the original Beardslee design.

A weakness of all of the above studies is that the participants are almost all of white, middle class backgrounds, creating a significant limitation in their generalisability. Podorefsky, McDonald-Dowdell, and Beardslee (2001), however, adapted Beardslee's interventions for low-income, ethnic minority

families, living in violent neighbourhoods. Using measures modified for this population, Podorefsky et al. found that both interventions had a positive impact on family communication and understanding. In the clinician-based intervention, parents reported improvements in child behaviour, self-understanding, and concerns about and focus on the child. The paper's focus on describing the process of adapting the intervention demonstrates the thorough, long-term work that contributed to the adapted interventions, but at the expense of any detailed statistical analyses. The report's simple, descriptive format of the results unfortunately makes the paper difficult to interpret and compare to other studies. Further, all sixteen participating families were single-parent families, potentially adding a confounding factor, although this is not discussed in the paper.

D'Angelo et al. (2009) again adapted Beardslee's interventions for Latino families by altering the language and context used. Using questionnaires and semi-structured interviews with nine families in a pilot study, D'Angelo et al. found improvements between pre- and post-intervention on mothers' Global Assessment Scale (GAS) scores, but not on child GAS scores since these were non-clinical at baseline. Mothers and children reported positive experiences of the group, although it could be argued that the face-to-face interview biased responses, whereas an anonymous questionnaire may have provided more balanced feedback. The authors acknowledge that additional measures are needed before firm conclusions can be drawn about the impact on parent and child well-being.

Solantaus, Toikka, Alasuutari, Beardslee, and Paavonen (2009) used a RCT with 119 families to test their adapted Beardslee interventions for use in Finland, and found that parents and children reported more positive relationships, increase in understanding, and decrease in worry, regardless of the condition they were assigned. However, the scores in the clinician-based intervention group were almost all significantly more improved than in the lecture-based group. Both groups perceived the intervention as positive, but parental perceptions of the clinician-based intervention were even more positive than that of the lecture intervention. It is unfortunate, however, that the authors' main focus is on parent outcomes, when the aim of such interventions is ultimately prevention of depression in children (Beardslee et al., 1999). Solantaus et al. state that they used the self-report Children's Depression Inventory, but report only baseline measures. They do offer additional data in their follow-up paper (Solantaus, Paavonen, Toikka, & Punamäki, 2010), suggesting that children's depression symptoms and pro-social behaviour improved following both interventions (although most strongly in the clinician-based group), and at 4, 10, and 18 month follow-up. However, this was solely based on parent report, again at the exclusion of any child opinions.

5.1.3. Other integrative designs.

As well as the studies using the Beardslee model, there exist other interventions based on the integrative models of depression transmission. Beach et al. (2008) reported a 7-week intervention with 98 African-American

families, compared to a control group receiving “minimum treatment”. The intervention involved parallel parent and child groups, each followed by a joint session to practise skills just learnt, such as family communication. Parents reported their own changes and their perceptions of their child’s changes, to the exclusion of any youth self-report. Parental depression improved in the intervention group, moderated by improvements in parenting, which could be thought to improve child outcomes. However, such outcomes were largely not reported. The only reported child changes were that the intervention marginally enhanced children’s intrapersonal competencies, as reported by parents. Although the sample size is good, the authors fail to consider that some of the changes reported may be related to the fact that these families’ results were drawn from a much larger, general population sample, whereby these families may have been influenced by being in a group with families without depression. This renders the study more difficult to compare to other studies where only parents with depression take part. However, the nature of this intervention, with considerable amounts of time dedicated to both children and parents, is perhaps an improvement on the Beardslee design which offers less contact time with children.

Another alternative design is described by Compas et al. (2009), who evaluated a family-based cognitive behavioural therapy (CBT) intervention (with child-only, parent-only and joint sessions) against a self-learning, written information condition. Across the 111 families, the results were mixed; some child self-report measures suggested a significant improvement in internalising symptoms in the intervention condition at 2, 6, and 12 month

follow-ups, but others were only significant after 12 months. There were equally mixed parent-reports of children's internalising symptoms. Overall, these results yielded small to medium effect sizes. Similarly, reports of externalising problems varied with the measure used; the data suggests that the intervention condition may have had some influence on adolescents' externalising problems, although not quite to a significant level. Further data analysis (Compas et al., 2010), revealed that the intervention condition improved parenting skills and adolescents' coping skills, both of which mediated the effect on adolescents' internalising and externalising symptoms. The relatively detailed report of results and statistical analyses in these papers makes them some of the most thoroughly evaluated of all the studies reviewed. However, the discrepancies found between different outcome measures render it impossible to draw firm conclusions. The study is, however, well grounded in theory and the authors usefully attempt to incorporate their findings back in to the integrative theory on which their intervention is based. As with Beach et al. (2008), these findings suggest that an intervention involving significant child, parent and whole family involvement with a clinician may be beneficial to both parents and children, but further data is required.

Another, similar intervention of a parent CBT group, parallel child CBT group, and whole-family sessions, is described by Riley et al. (2008). Outcome data for ten mothers and thirteen children is reported, which demonstrated improvements in "family togetherness" and in children's behavioural and internalising symptoms (small to moderate effect sizes) over the course of

the group. However, youth and parent reports of parental monitoring, supervision and consistency did not improve, and children actually reported a moderate increase in school maladjustment. The paper's thorough discussion of the theoretical basis, and detailed description of the intervention, is at the expense of any numerical reporting of data analysis, which is further limited by the small sample size. Additionally, other variables were not well controlled, such as the level and type of other mental health interventions that some parents and children were receiving. In a later paper, however, Valdez, Mills, Barrueco, Leis, and Riley (2011) helpfully report additional data analysis suggesting positive change following the intervention on child and parent symptoms and behaviours, family functioning, and parenting, with effect sizes ranging from .20 to 1.11. The authors do not discuss the discrepancy between their original paper which reported no change in parental monitoring, supervision and consistency, and this paper which reports positive changes to parenting. They do, however, confirm the large increase in child reported school maladjustment, and offer a thorough discussion of this issue.

5.1.4. Summary of studies based on an integrative framework.

These ten studies all incorporate at least some parent and child involvement, facilitating whole-family awareness of issues related to parental depression in order to try to reduce the likelihood of children developing depression. The whole-family involvement sits well in this field of research which has its foundations in systemic principles, with parent, child, and environmental

factors interlinked using the integrative theories of the transmission of depression. Such parent and child involvement perhaps prevents individuals from being singled-out and feeling blamed, which could add to the difficulties that may already be present.

However, this lack of focus on individuals leaves the research open to the possibility of many different variables being measured in several different ways, rendering it hard to draw firm conclusions across the studies about what may have changed and to what degree. Some studies collect only parent data, which could be said to be unhelpful given the aim of preventing childhood depression, although some include parent-reported child data, and some include child self-report data. Overall, the studies indicate at least some positive change, although the differences in what is measured as well as the large variation in sample sizes (from N=3 to N=167) do not paint a clear picture from which firm conclusions can be drawn.

5.2. Review of Studies Using Discrete Theoretical Models

The next group of 5 papers are those studies based on discrete theories of depression transmission, which focus on, and involve, either children or parents. The first three papers discussed in this section are those using a child (cognitive) theoretical base, with parenting theories used as the foundation for the final two papers.

5.2.1. Child / cognitive interventions.

Clarke et al. (2001) describe their RCT of a 15-session group CBT intervention for adolescent children of parents with depression, although parents had no involvement. Children with subsyndromal symptoms (some elevated ratings on measures of depression, not sufficient for a diagnosis) were included. Children in “usual care” were used as a control group. Significant group differences were found on two out of the three measures of depressive symptoms and also on interviewer-rated suicidal ideation items, suggesting symptoms had reduced over the course of the CBT group as compared to the control group. However, the third measure, a parent-report questionnaire, did not indicate such improvements. The improved self-report symptom scores remained significant in the intervention group at the 12-month follow-up, and this group were found to have a significantly lower incidence rate of depression within the 12 months after intervention than the control group, suggesting a preventative effect of the intervention. This significant effect continued but at diminished levels at 18-month and 24-month follow-ups. The number of participants in this study is one of its strengths (N = 94), as is the RCT design. However, the study lacks grounding in relevant theory, instead using an intervention that was designed for a high-risk subsyndromal school population, largely unrelated to parental depression.

Clarke et al. (2002) report a similar, 16-session group CBT intervention with the same focus as Clarke et al. (2001), but with currently-depressed

adolescent children of parents with depression. There were no significant effects of the group on any of the outcomes measured at post-treatment or later follow-up. As the authors mention, the non-significant results may be partly explained by the fact that the control group were in “usual care”, meaning that they were likely to be receiving some form of active treatment for their depression, whether medical or psychological. As above, however, there is minimal theoretical background given to the study, which results in the intervention having limited rationale.

Garber et al. (2009) report a larger (N = 316) RCT of a similar group CBT intervention, for adolescents whose parents have had depression or are currently depressed. The adolescents were selected on the basis that they had had a previous episode of depression or current subsyndromal symptoms. Results showed that children in the CBT group were less likely to experience a depressive episode in the follow-up period than the control group, and that any depressive symptoms declined at a significantly greater rate for these children over the course of the group and the following six months. The authors also report a significant moderator variable; rates of depressive episodes did not differ significantly between the two groups for adolescents whose parents were currently depressed at the start of the intervention. However, these rates of depressive episode were judged by the interviewers. When using an adolescent self-report measure, the group difference returned, in that adolescents in the CBT group with currently depressed parents reported significantly more reduction in symptoms over

time than adolescents in usual care with currently depressed parents. This raises an important issue of measurement which will be discussed below.

5.2.2. Parenting interventions.

Sanford et al. (2003) describe their parent psychoeducation group (N=21) focussing on specific issues for families where a parent has depression, in comparison with waiting-list control parents (N=23). The intervention group had improved parent-reported family-functioning, parenting sense of competence and family and parent conflict after intervention, although these differences were reduced when baseline depression was controlled for. Unfortunately, child self-report is missing, possibly because the children did not take part in this intervention. However, some self-report child data would nevertheless be of interest, since this is one of the main aims of the intervention, to prevent or improve depression in children through changes in the parent's understanding and parenting. The parent report data could be biased as a result of parents' improved depression symptoms and improved tolerance and patience that this may bring, or may be a result of wanting to show that they had been able to bring about some changes.

Similarly, Sanders and McFarland (2000) describe a study comparing their Behavioural Family Intervention (BFI) with a Cognitive Behavioural Family Intervention (CBFI). Although sounding like an integrative, family-based intervention, these are parent-only interventions, with child involvement limited to observational home visits by the clinician. Both interventions

improved mothers' depression and children's behaviour, but the effect at 6-month follow-up was stronger in the CBF1 group. Again this study lacks any child self-report and indeed the only child outcome data reported is the parent-rated CBCL, parent observation of their children, and clinician observation. However, given that this intervention was aimed at parents of younger children (aged 3 to 9 years, average age 4.4 years), only the oldest of the children in this study may have been able to complete self-report measures, making the parent-report a more acceptable and valid method of data collection. However, the study would need repeating with more families to determine its reliability and strength of its results, since only 47 families took part across both conditions.

5.2.3. Summary of studies based on discrete theories.

Due to the narrower focus of the theories on which these five studies are based, they offer somewhat more focused interventions, potentially allowing direct comparison with similar studies and easier replication. This is at the expense of greater family involvement, however, and could potentially create more of a sense of blame and therefore shame for participants. However, the participants did not report this, and in fact it could be argued that being in a group with peers in similar situations could in fact provide a normalising experience. It does, however, minimise the number of family members who can directly benefit from the intervention. The three studies based on the cognitive theory helpfully provide much child self-report data, as well as measuring incidence rates of depression in the follow-up period, a useful

indicator to use in prevention studies (Horowitz & Garber, 2006).

Unfortunately, the final two papers involve no child self-report, even from the older children, and it could be argued therefore that the ultimate goal of the interventions, to prevent transmission of depression from parents to children, is lost within the focus on parent-related data. Again, the varied sample sizes (from N=44 to N=316) do not make comparison easy.

6. Discussion

6.1. Summary of Findings

These fifteen studies aim to offer a psychological intervention to children, parents or families where one or both parents has depression, in order to prevent the development of depression in the children. Varied outcomes are reported, although overall most point towards at least some positive change in children's symptoms and functioning, with the long-term follow-up studies suggesting these changes are maintained to some degree, with children experiencing fewer depressive episodes. The studies based on integrative theories all involve both parents and children in the intervention, which highlights to the family the multidirectional nature of influences within the family and joint responsibility, and those interventions including some time with peers from other families may additionally provide some normalisation and peer-support. The other studies provide intervention to only children or parents, depending on which discrete theory they are based upon, which allows for a tighter focus and potentially easier comparison.

6.2. Methodological Considerations

There are several limitations in the methodology of these studies, restricting the conclusions that can be drawn. Not all studies have been rigorously followed up, and so longer-term comparisons are not possible. Given that this body of research is intended to have a preventative focus, long-term follow-up is essential, and this is one of the main limitations in some of these studies. Even where follow-up has been conducted (e.g., Beardslee et al., 1996), it is often unclear which families and exactly how many families were followed up when. This limits any conclusions that can be drawn about the impact on children and the preventative qualities of the interventions.

The mixed results are complicated by the different methods of measurement used. Some studies report mainly parent changes despite the focus being ultimately on improving child outcomes. Of those studies reporting child outcomes, the majority use parent-report measures, which in itself can be flawed if, for example, the parent's depression is lifting and this is impacting on their perception of their children. This is, of course, interesting in itself, although none of the studies analysed this. More child self-report in such studies could provide additional useful information about the impact of such interventions on children. However, the use of too many different measures and interviews can result in conflicting outcomes, rendering it impossible to draw firm conclusions, as in the Compas et al. (2009) study. This issue clearly highlights the importance of using reliable and valid measures

appropriate to the sample, but equally the importance of not relying solely on one outcome measure which may produce biased results.

Further, very few studies appear to have sought the children's opinions of the interventions, and where they have, there is a lack of consistency in the explanations given, resulting in exaggerated positive feedback. For instance, Beardslee, Wright, et al. (1997) report that children in the lecture group were happier with the intervention than children in the clinician-based group. Given that children do not take part in the lecture group, this would appear to be a concerning finding, possibly suggesting that the children found the clinician-based intervention difficult, as indeed Solantaus et al. (2009) consider.

Beardslee, Wright et al. (1997), however, simply suggest that children in the lecture group were attempting to please the assessor because it was the first and only time they had met them, implying that children in the clinician group would be more honest. This is in contrast to an earlier paper, however, when Beardslee et al. (1996) suggest that participants who had developed relationships with a clinician over the course of the clinician-based intervention, may in fact wish to report exaggerated positive changes.

Discrepancies such as this could suggest that some authors may have used their data to confirm hypotheses without fully considering alternative explanations, and highlight the importance of scrutinising the data carefully.

However, another area where this literature lacks strength is in reporting data. Not all of the papers give details of the data collected, instead summarising the findings in prose. Very few provide effect sizes consistently,

which is important when attempting to compare across studies. It seems that some papers do not report detailed results because of lack of space after describing the intervention and discussion of the findings, but also because at present there are so many different variables measured across the area of research that there appears to be confusion about what to report and why. This is an area where researchers could relatively easily make changes which would bring a better focus to the field and make progress easier to measure.

This issue of measurement is perhaps related to the theoretical underpinnings of this area of research, in that different theories point to different outcomes being measured. For example, the studies based on integrative theories, involving so many different factors, attempt to measure several different outcomes in different ways, resulting in unnecessary confusion. However, the two parent-focussed interventions also attempt to report various outcomes, but lack much child data, again lacking clarity or a comprehensive rationale. The three child-only intervention studies do, however, have much clearer reporting of measurement and results, with a focus on child internalising and externalising symptoms. Although these studies may therefore omit several important elements related to children's likelihood of developing depression (such as parental knowledge and awareness), they do provide much clearer, comparable data to enable the research to continue to develop. Perhaps then, the integrative theories, although more thorough, require more work to incorporate better ways of measuring targeted change.

Further, although all of the studies are attempting to prevent depression in young people, the age of the children targeted varies across studies, from as young as 3 years to late adolescence. If truly based on theory, the targeted children should be pre-pubescent in order to put changes in place before the likely age of onset of depression, but old enough to be able to understand, for example, a basic cognitive theory.

A related limitation is that there appears to be no consideration of differences between children whose parent has been depressed for a long time and those whose parent has more recent-onset depression, or indeed the age of the child at the time of the parent's first episode. This is important because it could be that the older the child is at the time of their parent's first episode, the more likely they are to have established coping strategies and so are less likely to be negatively affected (Goodman & Gotlib, 1999), or perhaps a child brought up from birth by a parent with depression may be better equipped to cope with future episodes if they have previously assimilated to the presentation and parenting style associated with low mood.

Further, the child's own level of depression symptoms varies across the studies, with one study actually targeting depressed adolescents (Clarke et al., 2002). This also makes it difficult to compare or make conclusions about prevention. Indeed, it was interesting that this study found no positive outcomes and provided minimal theoretical background, suggesting that interventions aimed at prevention need to be targeted more carefully,

grounded in the preventative, mechanistic theory base, and not confused with group treatment interventions for children with existing depression.

Finally, some of the samples included only families with maternal depression (e.g., D'Angelo et al., 2009; Riley et al., 2008), limiting the generalisability of their findings, especially given the possible differences between the significance of maternal and paternal depression (Tully, Iacono, & McGue, 2008).

Overall, however, many of the reviewed studies have good numbers of participants and many are randomized trials, all with the aim of preventing suffering in young people. The researchers have clearly dedicated much time and thought to the interventions, and attempt to measure some of the changes they hope to facilitate. They therefore provide a solid foundation for future prevention work in this field.

6.2.1. Suggestions for future research.

As well as the limitations discussed, future research should include qualitative studies, to gain a deeper understanding of the impact of such interventions, and more RCTs using control groups and also comparison groups with a measured intervention, to determine which aspects of such interventions enhance outcomes. Additional UK-based studies would help to determine their generalisability, and more longitudinal studies are needed to confirm their preventative effects. Further, studies with participants from

different backgrounds would be beneficial, including outreach to those families reluctant to opt-in, but therefore potentially most in need of support. Also important would be studies controlling other variables such as gender and self-esteem, to determine which individual, family and environmental factors may naturally prevent depression in these children, in order that resources can be targeted to those most in need.

6.3. Implications for Clinical Practice and Service Delivery

This review has highlighted the potential need for interventions with children of depressed parents, and has shown that such interventions may have some positive and protective effects, possibly preventing some symptoms of depression in this population. It is important that both child and adult mental health clinicians and other professionals involved with these families, become aware of the potential for positive change, and work together to implement such changes. At present, the majority of services in the UK remain solely adult- or child-focused, with adult mental health clinicians often feeling unable or ill-equipped to intervene to support clients' children (Hetherington & Baistow, 2001).

A more structured intervention, for example through organisations such as Young Carers, could be established, which would have the potential to create long-term positive changes for these families as well as potential cost savings, by preventing the need for subsequent mental health services for the children involved (Lynch et al., 2005). Of course, it may not be cost-

effective to offer such preventative interventions to all affected families (Yuh, Maloy, Kenney, & Reiss, 2006). However, families with fewer protective resources and higher levels of risk could be prioritised, depending on factors discussed within the integrative theories, such as the age and gender of the child, the presence of one versus two parents with depression, other stressors present in their lives, and the child's characteristics.

The possibility of introducing such preventative interventions more widely seems particularly salient not only given the significant increase in government funding dedicated to psychological therapies for adults with depression (DoH, 2008), but also with the current plans to dedicate additional funding for children and young people's psychological services (DoH, 2011). Although it remains to be seen which of the interventions is most effective in the long-term, some of the interventions discussed would be within the scope of Improving Access to Psychological Therapies (IAPT) services, perhaps especially the interventions based on CBT, since the therapists have a strong training background in this model (DoH, 2011). The family-based interventions would perhaps be better delivered by mental health teams with training in systemic practice. However, before such decisions could be made, more research is needed to determine which are the most effective interventions and for which populations.

7. Conclusion

Clinicians are beginning to recognise the value of interventions with a preventative focus to bolster resilience in children affected by parental depression, through psychoeducational, cognitive, behavioural, and systemic therapies. At present, this research is highly varied, each researcher using a particular theory or element of a theory of depression transmission to determine the focus of their intervention and outcome measures.

Nevertheless, the research provides a strong foundation for the potential for improving children's well-being and preventing development of depression.

Although not a direct aim of these interventions, some have also shown promise for improving parents' depression symptoms, which in turn has a positive impact on the children. Despite the limitations in the research, it highlights the value of working with more than just an individual client, instead encouraging resilience-building among the whole family. Although resource-heavy, such interventions could have preventative effects, thus reducing the need for additional resources by these families in the future.

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Table 1. Intervention Studies Based on Integrative Theories

No.	Study	No. of participants	Child age range	Study design and intervention	Results
1a	Beardslee et al. (1993)	Pilot study of 20 families: 12 in clinician-based intervention and 8 in lecture-based intervention	8-14 years	Randomized trial of the Beardslee design: Clinician-based intervention with family vs lecture intervention for parents	Both groups: Decrease in upset. Clinician-based group: More satisfaction with intervention & personal concerns addressed. Some additional behaviour & attitude changes.
1b	Beardslee, Wright, et al. (1997)	Further results (of up to 100 families including the 20 above) and follow-up after approximately 9-12 months	Now aged 8-16 years	As above	Clinician-based group: Children had higher levels of functioning post-intervention and at follow-up, and greater understanding of parental depression.
1c	Beardslee et al. (1996)	3-year follow-up of 51 parents of 26 families	Now aged 11–17 years	As above	Clinician-based group: Positive parental behaviour and attitude changes.
1d	Focht-Birkerts & Beardslee (2000)	6-year follow-up of 3 adolescents	Now aged 16-18 years	As above	Qualitative interviews: Some positive changes, more process related than symptom related.

No.	Study	No. of participants	Child age range	Study design and intervention	Results
2	Beardslee, Versage, et al. (1997)	37 families: 19 in clinician-based intervention, 18 in lecture-based intervention	8-15 years	Randomized trial of the Beardslee design: Clinician-based intervention with family vs lecture intervention for parents	Both groups: Significant improvements reported by parents on family understanding and communication, and satisfaction with material covered, though clinician intervention most beneficial. Clinician-based group: Child-reported increased understanding of parental depression.
3a	Beardslee et al. (2003)	1-year and 2.5-year follow-ups of 93 families	8-15 years at time of intervention	As above	Both groups: Children's internalising symptoms and understanding of parental mental health improved. Improved parents' child-related behaviours and attitudes, but especially strong in clinician-based group.
3b	Beardslee et al. (2007)	4.5 year follow-up of 91 families	8-15 years at time of intervention	As above	Both groups: Family functioning and parent and child symptoms improved. Clinician-based group: Significantly more gains on parents' child-related behaviours and attitudes, and in child-reported understanding of parental mental health.

No.	Study	No. of participants	Child age range	Study design and intervention	Results
4	Butler, Budman, & Beardslee (2000)	74 families	7-12 years	RCT: Videotape-based family depression program vs waiting list control group. Parent video, child video and parent manual about helping children to develop resilience and spotting signs and symptoms.	Video group: Improved parent-report of child functioning, support from spouse and ability to talk openly about depression with the family.
5	Podorefsky, McDonald-Dowdell, & Beardslee (2001)	16 single-parent families	Not reported	RCT of Beardslee design adapted for low-income, ethnic minority families, living in extreme poverty in violent areas	Both groups: Improved family communication and understanding. Clinician-based group: Global benefit, parent-reported improvements in child behaviour, self-understanding, and concerns about and focus on the child.
6	D'Angelo et al. (2009)	9 families	7-17 years	Pilot study of adapted Beardslee clinician-based intervention for low-income Latino families. No control or comparison groups.	Improvements to mothers' GAS scores but not child GAS scores (these were non-clinical at baseline). Positive experiences of the group reported by mothers and children.
7a	Solantaus et al. (2009)	119 families	8-16 years.	RCT of Beardslee design adapted for use in Finland	Both groups: Parents and children reported positive relationships, increase in understanding and decrease in worry. Parental perceptions of intervention especially positive in clinician-based group.

No.	Study	No. of participants	Child age range	Study design and intervention	Results
7b	Solantaus et al. (2010)	4-, 10-, and 18-month follow-up of between 78 and 106 families from Solantaus et al. (2009) study	8-16 years at time of intervention	RCT of Beardslee design adapted for use in Finland	Both groups: Parents reported improved child symptoms and prosocial behaviour.
8	Beach et al. (2008)	167 families: 98 families in SAAF, 69 in "minimum treatment"	Fifth grade children (average age 11 years)	Randomized trial of "Strong African American Families" (SAAF) programme vs "minimum treatment" group. 7 weeks, first hour concurrent parent and child groups, second hour joint to practise skills together. Aim to prevent substance use and risk behaviours.	SAAF group: Improvements in parental depression, mediated by improved parenting. Some parent-reports of improved youth intrapersonal confidence.
9a	Compas et al. (2009)	111 families: 56 in CBT group, 55 in written information condition	9-15 years	RCT of family group CBT vs written information self-learning. 3 sessions of group CBT together with up to 3 other families, then 5 sessions of separate parent groups and child groups. 4 (monthly) booster sessions.	CBT group: Reduction in depressive symptoms for both children and parents
9b	Compas et al. (2010)	Same study as above but now using only data from 1 child in each family (i.e. restricted sample): 111 parents, 111 children	9-15 years	As above	CBT group: Children's coping skills and parents' parenting skills improved, mediating the effect on the children's symptoms.

No.	Study	No. of participants	Child age range	Study design and intervention	Results
10a	Riley et al. (2008)	10 families in pilot study: 10 mothers, 13 children	9 – 16 years	Pilot study of “Keeping Families Strong” Programme. 10x90 min meetings. Group for parents and group for children conducted concurrently. Two follow-up groups.	Mainly positive findings on youth and parent reports of children’s behaviours and symptoms, and family cohesiveness. Some positive change to maternal symptoms.
10b	Valdez et al. (2011)	As above	As above	As above – additional data analysis.	Positive change reported by both parents and children on child and parent symptoms and behaviours, family functioning, and parenting.

Table 2. Intervention Studies Based on Discrete Theories

No.	Study	No. of participants	Child age range	Study design and Intervention	Results
11	Clarke et al. (2001)	94 adolescents: 45 in group CBT, 49 in usual care, all with subsyndromal symptoms of depression.	13-18 years	Randomized trial of group CBT vs usual care. 15-session peer-group CBT. Parents do not take part, other than to attend 3 information meetings.	CBT group: Reports of fewer “depressed days” and significant preventative impact, with lower incidence rates of depression.
12	Clarke et al. (2002)	88 adolescents: 41 in group CBT, 47 in usual care, all with current depression.	13-18 years	Randomized trial of group CBT vs usual care. 16-session peer-group CBT. Parents do not take part, other than to attend 3 information meetings.	No significant benefits of CBT group on symptoms of depression.

No.	Study	No. of participants	Child age range	Study design and intervention	Results
13	Garber et al. (2009)	316 adolescents with a previous episode of depression or current subsyndromal symptoms	13-17 years	RCT of group CBT vs usual care. 8-session peer-group CBT plus follow-up. Parents do not take part, other than to attend 3 information meetings.	CBT group: Significant preventative impact, with lower incidence rates of depression over follow-up period.
14	Sanford et al. (2003)	44 families	6 – 13 years	Parent psychoeducation group vs waiting-list control group. 8-week parent psychoeducation group focussing on specific issues for families where a parent has depression (e.g. child's withdrawal from peers)	Psychoeducation group: Improved self-reported family-functioning, parenting sense of competence and family & parent conflict. However, reduced effect when baseline depression was controlled for.
15	Sanders & McFarland (2000)	47 families	3 – 9 years	Behavioural family intervention (BFI) vs Cognitive behavioural family intervention (CBFI). Individual family intervention weekly for 12 weeks: 8 parent sessions in clinic and 4 feedback sessions at home (for observation of whole family). Parenting skills and behaviour management strategies, with additional cognitive strategies for depression in CBFI.	Both groups: Improved maternal depression and child behaviour. CBFI group: Stronger effects on maternal depression and child behaviour at 6-month follow-up.

Chapter 2: Empirical Paper

Resilience amongst Siblings of Children with Diabetes

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9. Abstract

Research suggests that the sibling relationship can have a significant impact on an individual's development during childhood, but that issues such as illness or disability in one sibling can have a detrimental effect on the psychological wellbeing of the other sibling(s) in the family. More recent research, however, suggests that alongside such negative outcomes there is also the potential for positive outcomes such as resilience, as a result of the difficult experience. This study investigated whether there is a difference in resilience levels between children with a sibling with diabetes, and children with a sibling with no health problems. Although hypothesised that the former group would demonstrate higher levels of resilience than the latter, due to the adversity and stressors experienced in relation their sibling's diagnosis, no group differences were found. It is concluded that in this sample at least, a diagnosis of diabetes does not create sufficiently significant adversity from which higher levels of resilience may develop. Future research should attempt to recruit a larger sample from a more diverse population. Clinical implications for paediatric clinicians are discussed.

10. Introduction

10.1. Family and Sibling Relationships and Systems

Decades of research and theory demonstrates the importance of the family to child well-being (e.g., Fraser, Kirby, & Smokowski, 2004). Families can be a significant protective factor for a developing child, or can hinder their development, posing more risk than protection (Fraser, 2004a). The reasons for this can stem both from factors within the family unit (Maccoby & Martin, 1983) as well as the complex influence of external factors upon the family. Indeed, Bronfenbrenner's (1986) ecological theory hypothesises that the family system is itself influenced by other, extrafamilial factors, and therefore that a child is nested within many interdependent systems. Fraser's (2004b) ecological, multisystems perspective simplifies but develops this theory, proposing a model using three systems-related domains (individual characteristics, family factors and the wider environment such as school and community) which interact to contribute to child development and well-being, with each domain itself comprising of a multitude of interacting factors.

Within the domain of family, for example, the sibling relationship is often the longest lasting relationship an individual has (Sanders, 2004) and can therefore exert significant influence on an individual across the lifespan (Pike, Coldwell, & Dunn, 2005; Stoneman, 1993). The quality of this relationship, and thus the impact it may have, seems itself to depend on many factors, such as the age and gender of the siblings, the wider family

context, and other biological, psychological, social, and environmental factors (Kilmer, 2006; Pike, Kretschmer, & Dunn, 2009; Sanders, 2004).

Since the sibling relationship and its related factors may significantly influence children's development, researchers have begun to study this relationship in depth, in order to further develop theory and clinical practice, for example in the field of family therapy (Minuchin, 2002). It has been found that there is great variability in the quality of sibling relationships, with some being positive, supportive and satisfying, and others less positive and more conflicting (Dunn, 2002; Pike et al., 2005). Sibling relationships seem to provide opportunities for learning about and experiencing difficult, potentially uninhibited, interpersonal emotions (Dunn, 2002), and can help children to develop social skills (Downey & Condrón, 2004).

10.2. Sibling Difficulties and Illness

New research, however, examines the effects on children of having a sibling with a difficulty, such as a physical or mental health problem, or learning disability, whereby some of the usual influential factors may be different or absent (Bellin, Bentley, & Sawin, 2009; Dia & Harrington, 2006; Kilmer, Cook, Taylor, Kane, & Clark, 2008; Schuntermann, 2007). It is thought that having a brother or sister with a mental or physical health problem or learning disability can lead children to experience mixed feelings of guilt, jealousy, embarrassment or shame, as well as putting pressures upon them

to provide extra care and support (Barlow & Ellard, 2006; Marshak, Seligman, & Prezant, 1999; McHale & Gamble, 1989; Sanders, 2004).

For instance, Taylor, Fuggle, and Charman (2001) asked siblings of children with physical illnesses to complete a questionnaire about their perceptions and attitudes towards their sibling's illness, and also assessed whether maternal report matched this, and the effect that any discrepancies between the reports had on the children. Taylor et al. found that the majority of the sample did not have adjustment problems as measured across the five subscales of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). However, one quarter of the children in the sample had levels of emotional symptoms (as measured by one of the subscales) that were significantly greater than would be expected in the general population. The authors also asked the children to rate their attitudes and perceptions towards their sibling's illness. They found that the closer the maternal ratings of their child's attitudes and perceptions to the child's self-reported perceptions, the better the adjustment outcome of the child, suggesting that family understanding and awareness aids adjustment in children who have siblings with a chronic health condition. This appears to support the ecological multisystems perspective (Fraser, 2004b), by demonstrating complex interplay between several factors accounting for a child's adjustment. However, the study relied mainly on maternal report, including only one child-report questionnaire regarding perception of the sibling. Given that parental report can differ significantly to child report as found in this study, and given that this lack of awareness itself may be a contributing

factor to the child's adjustment, it seems particularly important to include more child report measures in such research, to ensure validity (Barnett, 1993).

Other studies including more self-reports have, however, also found such interacting factors that seem to contribute towards the child's adjustment. For example, Bellin et al. (2009) investigated the effect of having a sibling with spina bifida, by asking children to complete five self-report measures². They found that individual, family and peer factors interacted to contribute towards a child's self-concept and behaviour.

Using child self-report as well as parent report, Listug-Lunde, Zevenbergen, and Petros (2008) found no differences between a group of siblings of children with Attention Deficit Hyperactivity Disorder (ADHD), and a control group, in terms of internalising problems, hyperactivity or attention problems. This may suggest, therefore, that siblings of children with difficulties do not necessarily develop problems with adjustment and functioning.

To address this possibility, there is a small, developing area of research investigating the phenomena of resilience and psychological growth in this sibling population. Findler and Vardi (2009) found that siblings of children with intellectual disabilities reported more psychological growth due to the

² These were The Child Attitude toward Illness Scale, The APGAR, The Sibling Relationship Questionnaire-Brief Version, The Social Support Scale for Children and The Children's Self-Concept Scale 2, see paper for author details

stresses they had faced living with their sibling, than children with typically developing siblings. This finding suggests that positive psychological outcomes are possible for children whose siblings face difficulties, and therefore the area warrants further research. If living with a sibling with a difficulty may help to foster psychological growth, further research may aid understanding of resilience and growth, and help clinicians to foster such positive outcomes amongst the families with whom they work, potentially preventing some of the negative effects that have previously been found (e.g., Barlow & Ellard, 2006). Indeed, although families of children with particular needs and difficulties may have more stressful lives than other families (Crnic & Lyons, 1993), the experience can lead to a more satisfying and richer life, aiding tolerance, understanding, and psychological strength (Knox, Parmenter, Atkinson, & Yazbeck, 2000; Stainton & Besser, 1998).

10.3. Siblings of Children with Diabetes

Diabetes affects more than 4% of people in the UK (Diabetes UK, 2010), and when diagnosed in childhood is usually Type 1 diabetes, although with rising obesity levels, prevalence rates of Type 2 diabetes are also increasing (Porter & Barrett, 2007). Sufferers of Type 1 are unable to produce insulin which is required to enable cells to absorb and use glucose. It therefore requires daily monitoring of blood sugar levels and diet, as well as daily insulin therapy and regular check-ups with a specialist (Styne, 2004). If untreated, it can lead to blindness, heart problems, kidney failure, and other cardiovascular risks. It is a life-threatening disease and therefore anxiety-

provoking for sufferers as well as friends and family, and can also be associated with a sense of stigma (Seiffge-Krenke, 2001). However, few studies to date have investigated the impact on siblings.

Hollidge (2001) used both parent and child report measures to study behavior, anxiety, depression and self-concept in 8- to 12-year-old siblings of children with diabetes, as well as a semi-structured interview to assess their feelings about living with their sibling with diabetes, worries about health, and communication patterns. The results indicated that these children had higher than average levels of anxiety. This anxiety was related to worries about their sibling's health, low self-concept related to being unable to live up to their own expectations of caring for their ill sibling, and some feelings of guilt and shame. Hollidge also found, however, that these children demonstrated high levels of competence that was likely to have developed in order to cope with the experience of living with their sibling's illness. Another study (Gallo & Szychlinski, 2003) found that children whose sibling had diabetes were at elevated risk for self-perception problems, but that this was mediated by family functioning.

In an exclusively qualitative study, using in-depth interviews with siblings of children with diabetes and their parents, Loos and Kelly (2006) found that these siblings had developed high levels of responsibility and maturity, as well as very close sibling relationships, despite being exposed to sometimes high levels of irritability or anger when their brother or sister was experiencing hypo- or hyperglycaemia.

More recently, Jackson, Richer, and Edge (2008) asked siblings aged 7 to 16 years, of children with diabetes, to complete questionnaires assessing their cognitive appraisals and coping strategies, as well as a semi-structured interview. Parents also completed three measures. Scores on the parent-report SDQ suggested that despite the additional stress of living with their brother or sister with diabetes, these children were actually better adjusted than normative data would suggest for this age range. It may be possible therefore, that siblings of children with diabetes are not only better adjusted than the average population, but could also display higher resilience due to these same stressors that have helped them to become better adjusted.

10.4. Resilience

Resilience has been studied over the past thirty years in three main waves of investigation (O'Dougherty-Wright & Masten, 2005). Initially, resilience amongst individuals was simply described, then more dynamic, interactive, systemic theories were developed (Fraser et al., 2004) which have led to attempts to foster resilience through preventative interventions (e.g., Sandler, Wolchik, Davis, Haine, & Ayers, 2003). Although there has been much debate over these three decades, resilience has now come to be defined as, "a pattern of positive adaptation in the context of past or present adversity" (O'Dougherty-Wright & Masten, 2005, p.19) and "positive outcomes in the face of risk" (Fraser et al., 2004, p. 22). Unlike psychological growth following adversity, which refers to positive changes beyond an individual's previous level of functioning, resilience is often thought of as the ability to function at

normal levels despite adversity, or to return to this level of functioning once the adversity has ended (Joseph, Knibbs, & Hobbs, 2007; Kilmer, 2006). Some have therefore defined resilience as the ability to bounce back from adversity to competent levels of functioning (Masten & Coatsworth, 1995). Rather than being stable over time, however, it is thought to be a “relative as opposed to fixed [...] concept” (Luthar, Cicchetti, & Becker, 2000, p.544), which can change over time within an individual.

It is thought that a certain amount of stress or risk can strengthen some individuals' competent functioning, and that resilience develops from multi-directional interactions between adversity, individual strengths, and wider contextual protective factors (Fraser et al., 2004; Garmezy, 1993; Rutter, 2000). For instance, adults and children with higher intellectual abilities, self-esteem or self-regulation skills are more likely to demonstrate resilience, as are children with better family functioning or links to caring adults in their family or wider community, although the exact mechanisms of these processes are unclear (Masten, 2001; O'Dougherty-Wright & Masten, 2005).

11. Aims and Research Question

The present study therefore hopes to extend this area of research by investigating resilience among siblings of children with diabetes, as reported by the children themselves. Although some studies have found predominantly negative outcomes (Gallo & Szyclinski, 2003; Hollidge, 2001), other studies (Findler & Vardi, 2009; Jackson et al., 2008) have found

more positive outcomes, such as adaptation and psychological growth due to experiencing the stressors and responsibilities of living with a sibling with a difficulty. The present study asks, therefore, whether children with a sibling with diabetes demonstrate higher levels of resilience than similar children whose siblings have no health conditions (the control group), meaning they are more likely to be able to return to previous levels of functioning following adversity. Other possible influencing factors of self-esteem, cognitive ability, and family functioning (Masten, 2001; O'Dougherty-Wright & Masten, 2005) will be measured and controlled for within the analysis, to determine as far as possible whether any difference in levels of resilience between the two groups may be due to the stressors involved in living with a sibling with diabetes.

11.1. Hypothesis

It is hypothesized that children with a sibling with diabetes will demonstrate higher levels of resilience than the control group, possibly due to the stressors they have faced as a result of their brother or sister's diabetes. The null hypothesis therefore, is that there will be no differences between the two groups on the measure of resilience.

12. Method

12.1. Design

This study used a between-participants design with two groups. The diabetes group, recruited through hospitals, consisted of children who have a sibling with diabetes. The control group, recruited through a school, comprised children with a sibling with no health problems requiring regular specialist medical appointments. Validated scales were used to measure the dependent variable of resilience, as well as the potential covariates of self-esteem, cognitive ability, and family functioning. Quantitative statistical methods were used to analyse the data.

A priori power analysis using the results of Findler and Vardi's (2009) study suggested that the total number of participants required in the present study was 23, when calculated with power set at .80. However, Cohen (1992) recommends recruiting 26 participants per group for a study comparing two groups requiring a large effect size with statistical significance at .05. Therefore, it was hoped that 30 children could be recruited to each group to reach sufficient power, leaving some flexibility should any participants withdraw from the study. Approximately one hundred information packs were given out by the school, and approximately ninety packs were given out across three hospitals, in order to try to meet this target sample size. Despite this strategy, however, the desired sample size was not reached, although the final sample size was larger than the 23 suggested by the a priori power analysis.

12.2. Participants

12.2.1. Diabetes group

The diabetes group consisted of 12 children and young people aged 11 to 17 years (mean age 14 years, SD 2.15), of which five were male and seven were female. All of the siblings had a diagnosis of Type 1 Diabetes and saw a specialist paediatrician at the hospital every three months. Three of the siblings had a comorbid diagnosis of coeliac disease. Participants were recruited through children's diabetes departments at local hospitals (see Appendices 1 to 3 for parent cover letters, information sheets, and consent forms). All of the participants lived with their sibling all of the time, and had done so all of their lives since the birth of the youngest sibling. All twelve had the same mother as their sibling, and nine had the same father. Participants were included if they did not have a health problem themselves, or a learning disability that may have made participating difficult. All of the participants and their families were white.

12.2.2. Control group

The control group comprised 21 children aged 11 to 17 years (mean age 14 years, SD 1.87), including eight males and thirteen females. These children had one or more sibling(s) without any health problems requiring regular specialist medical appointments. This group was recruited through a local secondary school. Seventeen of the participants lived with their sibling all of

the time and had done so all of their lives. All participants had the same mother as their sibling, and twenty had the same father. Twenty of the participants were white.

12.3. Materials

12.3.1. Resilience

The Resiliency Scales for Children and Adolescents: A Profile of Personal Strengths (RSCA; Prince-Embury, 2007) was used as a measure of resilience due to its strong psychometric properties. The 64-item questionnaire consists of three main scales measuring Sense of Mastery, Sense of Relatedness and Emotional Reactivity, which can be combined to measure Personal Resources and Vulnerability. The measure is suitable for use with young people aged 9 to 18 years. Participants are asked to answer questions about themselves on a 5-point Likert scale (see Appendix 4).

The measure offers high internal consistency reliability across the age range, with Cronbach's alpha ranging from .56 to .95, with 90% being above .70, the acceptable level according to Nunnally (1978). The measure can also be considered reliable over time, with test-retest correlations ranging from .79 to .88, suggesting moderate to high reliability (Prince-Embury, 2007). Further, factor analysis confirmed that the three-factor model (Sense of Mastery, Sense of Relatedness and Emotional Reactivity) is the best fit, suggesting a

good level of internal validity across the tool. Correlations with other measures have also confirmed external validity (Prince-Embury, 2007).

12.3.2. Self-esteem

The 58-item Coopersmith Self-Esteem Inventory (CSEI; Coopersmith, 1981) was used, which gives a single score for a person's self-esteem, and is suitable for use with young people, asking them to rate each statement "Like Me" or "Unlike Me" (see Appendix 5). It is strongly recommended for use in research (Sewell, 1985), and has been shown to have high internal consistency reliability (alpha coefficient ranging from .87 to .92; Chiu, 1988), and test re-test reliability ($r = .73$ to $.85$; Chiu, 1985), and good convergent validity ($r = .60$; Crandall, 1973).

12.3.3. Family functioning

The revised Family APGAR (Austin & Huberty, 1989) assesses a child's perception of family functioning and comprises 5 questions to assess Family Adaptation, Partnership, Growth, Affection and Resolve (see Appendix 6, part of the participant demographic questionnaire). It has been shown to have good test re-test reliability ($r = .73$), good internal consistency reliability (mean alpha coefficient = $.70$) and acceptable internal validity (r ranges from $.32$ to $.52$; Austin & Huberty, 1989). Convergent validity has been demonstrated using the original 5-item APGAR (Good, Smilkstein, Good, Shaffer, & Arons, 1979).

12.3.4. Intellectual ability

Ability was measured using the Matrix Reasoning subtest of the Wechsler Abbreviated Scale of Intelligence (WASI; The Psychological Corporation, 1999). This subtest assesses nonverbal intellectual ability and is derived from the Wechsler Adult Intelligence Scale – Third Edition (WAIS-III; The Psychological Corporation, 1997) and the Wechsler Intelligence Scale for Children – Third Edition (WISC-III; The Psychological Corporation, 1991). As a test of nonverbal ability, it does not assess directly for verbal ability, but has a strong association with general intellectual ability (Kamphaus, 1993). It was therefore used as a stand-alone test to minimise the length of testing sessions, whilst giving an estimate of the participant's ability level (see Appendix 7 for a sample item).

The subtest has good internal consistency reliability and test-retest reliability (The Psychological Corporation, 1999). External validity is also strong, as demonstrated by correlation coefficients with the WISC-III, and internal validity has been shown to be high across all four subtests of the WASI, with all inter-correlations being significant in the anticipated direction (The Psychological Corporation, 1999).

12.3.5. Parent and participant questionnaires

Parents were asked to complete a demographic questionnaire (see Appendix 8) designed by the researcher, to gather information such as age, gender

and family composition. Participants were also asked to complete a question about their age and also their opinion of having a sibling (see Appendix 6).

12.4. Procedure

The procedure and recruitment process were approved by all relevant ethics bodies (see Appendix 9), and were the same for both groups, the only difference being the initial recruitment via school (control group) or hospital (diabetes group).

The parents of potential participants were given or sent information sheets and a “consent to be contacted” form, along with a covering letter and stamped addressed envelope, by the school or hospital. Once the “consent to be contacted” form was received, parents were contacted by telephone and given further information about the study and had any questions answered. If the parent and child were then happy to participate, a home visit was arranged. Since the research was interested in children in their family context, it was deemed most appropriate to carry out the research in the home setting, in order that the participants felt most comfortable, and therefore that the results may have higher validity.

At the home visit, the research was explained again and information sheets discussed with parents and participants. Full verbal and written consent was obtained from both the parent and participant, and the questionnaires were explained. The parent and participant were asked to complete their

questionnaires separately, and finally the participant was asked to complete the Matrix Reasoning task, facilitated by the researcher. Parents were told they could be present if the parent and child wanted this, but that they could not provide any help with the task.

13. Results

13.1. Descriptive Statistics

Table 1 presents the mean scores for all of the measures used. As can be seen, these scores are similar for both groups, both before controlling for the covariates and following the adjustment.

Table 1. Mean Scores for Both Groups

	Unadjusted Mean (SD)		Adjusted Mean (SE)	
	Diabetes Group (N = 12)	Control Group (N = 21)	Diabetes Group (N = 12)	Control Group (N = 21)
RSCA Personal Resources	50.67 (7.45)	51.52 (9.81)	50.34 (1.93)	51.71 (1.45)
RSCA Vulnerability	49.67 (6.44)	48.33 (9.76)	49.48 (1.74)	48.44 (1.31)
RSCA Sense of Mastery	49.25 (7.28)	50.62 (9.99)	48.89 (2.04)	50.83 (1.53)
RSCA Sense of Relatedness	52.58 (7.28)	53.29 (8.69)	52.31 (1.83)	53.45 (1.37)
RSCA Emotional Reactivity	50.17 (5.84)	48.24 (9.07)	49.57 (1.95)	48.58 (1.46)
CSEI	37.75 (6.27)	39.26 (8.09)	-	-
APGAR	15.50 (3.12)	14.86 (2.63)	-	-
Matrix Reasoning	52.58 (7.09)	52.52 (5.78)	-	-

Note. RSCA = Resiliency Scales for Children and Adolescents; CSEI = Coopersmith Self-Esteem Inventory; APGAR = Family functioning measure.

13.2. Preliminary Data Screening and Assumption Testing

Given the design of the study, the intended statistical analysis to be used was Analysis of Covariance (ANCOVA), conducting one analysis per subscale of the RSCA, although using the Personal Resources Index as the main measure of resilience, since this captures the two positive subscales of Sense of Mastery and Sense of Relatedness. Self-esteem, cognitive ability, and family functioning were to be controlled for in order to remove the influence they had on the RSCA scores, leaving any difference in resilience levels between the groups due to the different sibling experience as far as possible.

Initial data screening showed there were no outliers or missing data. All assumptions of ANCOVA were then tested. The three covariates were not found to correlate strongly with one another, with all r values (.12, .15 and .57) being considerably lower than .80, which would be considered too strong a relationship (Pallant, 2007).

13.2.1. Linearity

Linearity was then analysed using scatter plots (see Appendix 10). For both groups, linear relationships were found between the dependent variable, the RSCA scales, and the CSEI (self-esteem), and between the RSCA scales and the APGAR (family functioning). These two, the CSEI and the APGAR, were therefore treated as covariates, as anticipated.

There was no linear relationship, however, between the Matrix Reasoning and any of the RSCA scales, and therefore Matrix Reasoning was not used as a covariate within the analyses. Further, for the diabetes group only, the APGAR did not demonstrate a linear relationship with the RSCA subscale of Emotional Reactivity, and therefore because this assumption could not be met for both groups, the Emotional Reactivity subscale was left out of the ANCOVA analyses.

Therefore, ANCOVAs were conducted for four of the RSCA subscales (Personal Resources, Vulnerability, Sense of Mastery, Sense of Relatedness). Due to this number of analyses being conducted, Bonferroni adjustment was applied in order to decrease the chance of a Type 1 error, incorrectly finding a significant result. The intended alpha level of 0.05 was therefore divided by four, resulting in an adjusted alpha level of 0.01.

13.2.2. Homogeneity of regression slopes

In addition to visual inspection of regression slopes on the scatter plots, the assumption of homogeneity was tested statistically, for any significant interaction between the independent variable (group), and the covariates to be used (the APGAR and the CSEI). No significant interaction between group and the APGAR, or group and the CSEI, was found for any of the RSCA subscales, with significance values ranging from .54 to .91, all substantially greater than .05. Therefore the assumption of homogeneity was not violated.

13.3. ANCOVA

After controlling for self-esteem and family functioning, no significant group differences in levels of resilience were found on any of the RSCA scales, suggesting that both groups of participants had similar levels of resilience. No differences were found on the Personal Resources scores, $F(1, 29) = .32$, $p = .58$, partial eta squared = .01, the Vulnerability scores, $F(1, 29) = .22$, $p = .64$, partial eta squared = .01, the Sense of Mastery scores, $F(1, 29) = .57$, $p = .46$, partial eta squared = .02, or the Sense of Relatedness scores, $F(1, 29) = .24$, $p = .63$, partial eta squared = .01. As can be seen, not only are there no significant differences, but the effect sizes are also very small for each analysis, as indicated by the partial eta squared values.

13.4. Power Analysis

Power analysis revealed that in this study, power = .34 (with alpha set at .01), suggesting that the study had very little power to detect any real differences between the two groups. Stevens (1996) suggests that adjusted alpha levels are acceptable to compensate for small sample sizes, however even when alpha was increased to the original level prior to the Bonferroni adjustment (.05), power = .60, still indicating only a 60 percent chance of detecting a difference. Therefore, the non-significant results of the ANCOVA analyses, above, must be interpreted with some caution, although given the very small effect sizes, it is likely that the lack of any meaningful differences between the two groups is indeed justified.

14. Discussion

The findings of this research suggest that there may be no difference in resilience levels amongst children with a sibling with diabetes and children with a sibling with no medical problems requiring specialist treatment.

Although previous research has demonstrated higher than average levels of adjustment in siblings of children with diabetes (Jackson et al., 2008), this is the first piece of research investigating the phenomenon of resilience in this population. It is hoped that these findings therefore advance this field slightly, by demonstrating further evidence to counter the solely negative findings of much other research measuring factors such as anxiety, which, although important, is undoubtedly not the only possible outcome for these children. This research therefore highlights the potential for more optimistic outcomes.

The proposed hypothesis, however, that siblings of children with diabetes may demonstrate higher levels of resilience than the control group children, was not supported. It was anticipated that due to the additional stressors placed upon siblings of children with diabetes, they may develop higher levels of resilience. However, both groups showed similar levels of resilience, with no significant difference detected. When compared to population norms, the mean RSCA subscale scores for both groups all fell within the “average” score range of 45 to 54 (Prince-Embury, 2007). Only scores of 55 and above would be considered as “above average” levels of resilience.

This finding of no significant group difference could be accounted for by the fact that the children in the study appeared to see their sibling's diabetes as part of life, rather than as a stressor, and had adapted to any disruptions that the illness created. Indeed, previous studies have shown that children with a sibling with a difficulty do not necessarily perceive life as more stressful than those with typically developing siblings (Findler & Vardi, 2009), and comments from participants in the present study suggested similar feelings. Therefore, these young people may not have experienced sufficient adversity to develop higher levels of resilience.

In addition, although it may create additional stress, living with a sibling with a somewhat manageable condition like diabetes is perhaps not as difficult or frightening as other life-threatening illnesses which are less easily managed, so not creating sufficiently high levels of adversity from which higher levels of resilience can develop. Indeed, researchers agree that to develop significantly elevated levels of resilience, an individual needs to experience significant and serious adversity (Bellin & Kovacs, 2006; Masten, 2001; Rutter, 2000). It is possible that families with a child with less easily managed diabetes may find the illness considerably more stressful, and as a result, not have the time or resources to opt in to research studies. It is therefore possible that those children who have experienced greater adversity as a result of their brother or sister's diabetes, were not included in the study.

It is interesting, however, that all twelve participants in this group were older than their sibling with diabetes. It has previously been argued that children

born in to a family where an older sibling has a difficulty, enter the family at a time when this difficulty has been worked through and the family system has adapted and settled (Hodapp & Urbano, 2007). As such, younger siblings show better adjustment than older siblings because they did not experience the turmoil at the time of the discovery of the sibling's difficulty (Hodapp & Urbano, 2007), but are therefore not in a position to develop resilience from this as they did not experience the initial adversity. Consequently, it has been suggested that older siblings, who do experience this turmoil as their younger sibling's difficulty is discovered, are in a position to develop resilience and psychological growth due to these very stressors (Findler & Vardi, 2009). However, these suggestions have come from learning disability research, rather than research with families in which there is a child with a chronic physical illness such as diabetes. It is therefore possible that the older siblings in the present study, who demonstrated no higher levels of resilience than the control group, experienced anxiety and turmoil at the time of their younger sibling's diagnosis, but that the nature of being given a diagnosis of an illness that is now less life-limiting than it once was, does not create the same level of distress in the family as a diagnosis of a learning disability. Further, some of the families in this study talked of knowing wider family members with diabetes, suggesting that these families had additional resources and knowledge of the illness to draw upon, making the adaptation process somewhat easier.

14.1. Limitations and Future Research

Although this study has several strengths, it also has many limitations.

Firstly, the small numbers of participants limits the conclusions that can be drawn. Services were extremely busy and not all services approached were able to offer help with recruitment due to staff shortages and limited resources. Further, some families felt that they did not have sufficient time to dedicate to the research, with the many other demands already on their time. Future research should attempt to recruit more participants in order that the study has more power. As it stands, the interpretation of the non-significant results, above, must be taken with some caution, as the lack of power in this study could be preventing any real differences between these two groups from being detected.

Secondly, full intellectual ability was not measured but instead approximated using the Matrix Reasoning task alone. Although it was important not to make the data collection session overly long with the risk of affecting the concentration of the participants, it could be said that this variable would be a more reliable covariate if it were measured completely, perhaps using the whole WASI.

Thirdly, potential confounding factors such as other illnesses or conflicts in the family, or bullying at school, were not identified, which could have a significant impact on a child's level of resilience and self-esteem, as well as, potentially, their ability to focus on the questionnaires. Also, although not

assessed formally, a large majority of the sample appeared to be from middle class families, thus restricting the sample, and all participants were from one city in the Midlands and its surrounding areas, again limiting the generalisability of the findings. Related to these issues, the difficulty with the recruitment method used was that only willing families put themselves forward to participate, again limiting the types of families that were involved in the study, and therefore the conclusions that can be drawn. Future research should attempt to recruit participants from more diverse populations.

Additionally, the sample was not restricted to those children whose siblings had received their diagnosis in a particular time period or at a particular age, but instead included children whose siblings had only recently been diagnosed with diabetes as well as those who had had many years to adjust to this. It is not possible therefore to draw specific conclusions from this sample with regards to adjustment and resilience over time from diagnosis. This may be an interesting variable to study in future research.

Finally, the age range of the participants, from 11 to 17 years, was broad enough to capture experiences across this stage of development, but not narrow enough to draw specific conclusions about children at a particular age or developmental stage. Given the small numbers of participants, it was also not possible to split this sample to assess possible differences at different ages. Research with a larger sample may be able to assess such differences.

Future research could also build on these findings by investigating resilience in siblings of children with health conditions other than diabetes, including physical and mental health difficulties and learning disabilities. It would be helpful to gain a much deeper understanding of the variables that may contribute to a child developing resilience in the face of such adversity, as well as variables that can hinder this development.

14.2. Clinical Implications

The results from the sample studied suggest that children who have a sibling requiring specialist medical treatment have similar levels of resilience to those whose siblings require no such intervention, suggesting that the research with predominantly negative findings (Barlow & Ellard, 2006; Gallo & Szychliniski, 2003; Marshak et al., 1999; McHale & Gamble, 1989; Sanders, 2004) needs to be reconsidered in relation to the potential for positive, or at least non-negative, outcomes among these children. These findings are important to clinicians in a wide variety of settings, but perhaps particularly to those working in paediatrics.

Clearly, siblings are not the focus of paediatric medical staff who are working with the unwell child. However, this research has highlighted that the negative findings of other studies is not an inevitability and therefore could be avoidable, suggesting that preventative interventions to strengthen resilience in this often overlooked group, particularly in vulnerable families, is important. Such interventions could target risk reduction and also strengthen protective

factors, potentially leading to very different outcomes (Bellin & Kovacs, 2006; Masten, 2001). Currently, only those families with very obvious difficulties or risks are likely to be detected by paediatric clinicians due to child protection training (Ayonrinde & Payne, 2006), but a short screening tool could be introduced at routine assessments to assess for early signs of resilience or vulnerability in siblings, to prevent later difficulties. If clinicians working with these families were aware of potentially important variables including strengths and vulnerability factors such as self-esteem and family functioning, it may be possible that families in need, including vulnerable siblings, could be signposted to targeted support services, bolstering resilience in order that these children can cope with the demands of their sibling's illness, possibly preventing negative consequences.

Currently, clinicians are aware of the stressful nature of having diabetes for the ill child and also for the parents, who are often assumed to take responsibility (Seiffge-Krenke, 2001), but are perhaps less focused on the impact on siblings, despite these children often taking much responsibility for their brother or sister, and therefore suffering a great deal of stress themselves. Because diabetes is often an unexpected or non-normative stress, this can have a greater impact on young people during their development than on adults (Hauser & Bowlds, 1990), and can easily lead to maladaptive outcomes, as has been seen in some research. Therefore, it could be said that the wellbeing of the siblings is just as important as parental adaptation and wellbeing, and therefore should start to become an area of focus for clinicians in the field.

15. Conclusion

The present study demonstrated that there may be no differences in levels of resilience between children who have a sibling with diabetes, and those with a sibling with no health problems requiring specialist treatment. This suggests that the sibling's diagnosis is not always experienced as a highly stressful adversity which could result in greater resilience, and that any stressors that are associated with this diagnosis do not, therefore, necessarily result in a negative outcome for these young people, but can result in the same levels of resilient functioning as children whose siblings do not have the illness. It may be helpful for clinicians working in paediatric settings to screen for those families who are finding the experience more stressful, in order that vulnerable siblings could receive appropriate support, potentially building more resilience from the experience.

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Chapter 3: Reflective Paper

Being Resilient Within Systems: Reflections on the Research Process

Chapter word count (excluding references): 3107

17. Abstract

The process of creating this thesis has provided me with many opportunities upon which to reflect, and from which to learn and develop. This paper discusses some of the experiences I have had over the course of the two or three years from planning to write-up, and the things that I have gained from these experiences. It starts with an introduction explaining where the original ideas came from for the topic areas covered in the thesis, and then discusses the experiences I had with the children and families at the centre of the empirical research paper, and reflections on these. I then discuss my diverse experiences of working with teams and services, and conclude with some clinical and personal reflections.

18. Introduction and Context

The ideas for this thesis stemmed from a combination of contributory influences over my psychology career to date, starting as an undergraduate with the study of systemic theory and positive psychology. During my role as assistant psychologist in a Child and Adolescent Mental Health Service (CAMHS), I then became interested in family systems, and was often struck by the family relationships that were presented in appointments. The child at the focus of the appointment was often treated, at least on the surface, quite differently to their sibling, and one sibling relationship was clearly different to the next. It was from these experiences that I began to wonder what these families were like in their home environment, and whether what was displayed in the clinic room was representative of what happened at home, and in particular, how the siblings of the target child may be affected by the difficulties they faced. I was struck by one particular family, who, over the course of the intervention, seemed to alter many of their intra-familial relationships for the better. My idea developed further when on placement in an adult mental health setting, listening to clients talk about the concern they felt for their children, and the impact that their mental health may be having on their sons and daughters. I wanted to know more about the experiences of these children, and whether there was reason for these parents to be concerned, but also whether these young people were able to develop more positive attributes like resilience, from the experience.

Putting these ideas and influences together, then, I was curious to know more about resilience in families who were facing difficulties, and to pay particular attention to the siblings and children of clients facing a physical or mental health problem requiring specialist treatment. This reflective paper focuses on the empirical study rather than the literature review, discussing the process of carrying out new research with a sibling population.

19. Childhood Resilience

Resilience was a concept that I had been interested in for some time before starting this research, and yet I was not prepared for quite how amazed I would be by the children and families I met. The majority of the children and young people at the centre of this research, those with a sibling with diabetes, struck me as being strong, independent children, who cared very much for their sibling and often took responsibility for them, without protest or reluctance. It was clear from just meeting these young people that they were probably resilient individuals, who had adjusted to living with their brother or sister's potentially life-threatening illness, and indeed demonstrated taking an active interest in the health and well-being of their sibling. One participant told me that having a sister with diabetes had helped him to understand the condition in depth, and he had proceeded to teach a biology lesson at school in order to share this with his classmates, feeling it was important to raise awareness. Another participant discussed a time shortly after his sister's diagnosis when he detected she was hypoglycaemic, and successfully raised the alarm to his parents who had believed she was simply having a tantrum. I

remember feeling quite moved by these stories, both of which were told matter-of-factly, as if they were nothing remarkable. Seeing the challenges that these families faced on a daily basis to manage the diabetes, certainly put my research challenges in to perspective, and helped me to reflect on life's real stresses, allowing research set-backs to appear insignificant in comparison.

20. Working within a New System

More broadly, the experience of carrying out the research in participants' homes left me with a sense of privilege that I had not anticipated. I was, without exception, warmly welcomed, and families were interested to hear about the research. This also helped me to feel I was doing a worthwhile piece of research, as well as confirming what I had suspected about the benefits of doing research in the home setting, helping me to get a better sense of these families that I would be writing about. I was struck by the ease with which the families allowed me to become a part of their system for a short time whilst gathering the data, highlighting to me their flexibility and adaptability. Speaking to these families left me with a humbling feeling, realising that no matter what difficulties they were having in their life, facing a life-threatening illness on a daily basis, they remained generous enough to welcome me and take a genuine interest in the research. They were offered nothing tangible in return for their time, and the whole experience felt incredibly rewarding on my part.

It did, however, leave me wondering about those families who had not agreed to be contacted about the research, and feeling like I was perhaps doing them a disservice by not representing them within my findings. It is possible that those families are the ones with more stressors and perhaps lower resilience, and I still do feel that my research results are biased in favour of those families with more resources. This is, of course, a drawback of any opt-in research, but it nevertheless leaves me with a strong sense of injustice, feeling somewhat saddened at the inequality. I also reflected on this clinically, raising my awareness that as a clinician I have a duty to be aware of those families who may be in need of services, but who find it hard to engage, and offer outreach services wherever possible.

21. Working in Wider Systems

21.1. Recruiting Teams and Services

Prior to meeting the families, there were several stages to progress through, namely gaining ethical approval and contacting relevant services to help with recruitment. I realised at the start of this process that I would need to adapt to various different systems and be prepared for the difficulties that this may bring. The first stage, gaining ethical approval, involved applying to various different ethics bodies, each with its own specific requirements and timescales. These were really the first systems that I had to become familiar with, and I surprised myself with the range of emotions that this could bring. Experiencing the lack of control over the process and the differences

between each team's speed and efficiency, helped me to learn more about areas that I need to develop, such as feeling more comfortable with delegation. Although a highly frustrating process and one that seemed more complex than necessary, I feel I learnt a lot about myself from this, as well as appreciating the importance of ethical rigour.

The next stage, asking services to help with recruitment, was also a learning curve. As would be expected, some services were more amenable to helping than others, but what took me by surprise was that some services with no connection to me at all, were extremely enthusiastic about being involved. As with the families, these services only benefited in a small way by learning of the results of the research, but had very little else to gain from assisting me, and indeed it would require giving up some of their valuable time. These aspects of the research were interesting in themselves, highlighting professional dedication and human altruism. It was interesting for me to temporarily become a part of these systems, and again the feeling of being welcome, and people's flexibility to help with my research despite all of the other demands on their time, was astounding. My contact with all of these services made me think about my own future career, and how important it will be to ensure that whatever team I become a part of, to always try to be flexible and welcoming to other people in need of the team's help.

There were of course some services that found it harder to help due to their caseloads and other commitments. One service I visited for two pre-arranged visits, only to find on both occasions that they were not expecting me and

were unavailable for meetings. This was my first experience of a service not holding me in mind, and it highlighted how different this made me feel to those services who had successfully arranged individual or team meetings for me to attend. Particularly by the second unsuccessful meeting, I was beginning to feel quite despondent, and any further attempts to make successful contact felt futile. On reflection, I believe that apart from my own wasted time, one of the main reasons for my despondency was the lack of being held in mind, and although I was never able to recruit successfully through this service, it taught me the importance of holding clients in mind, made especially important given the sensitive nature of the topics they share with us as psychologists. Although already aware of this, my experience with this service made me more conscious of how essential it can be to a therapeutic alliance to be on time for clients, to be able to recall details of discussions from session to session, and to be tuned in to their responses within sessions, making it a safe space and instilling a sense of hope and optimism.

Of course, the experience also made me think about what it must be like to work in such a large hospital system, and appreciate the huge demands on these clinicians' time. I sensed that the missed meetings had been a genuine oversight, with staff being too busy and distracted with the immediate and essential aspects of their jobs, that is, taking care of their patients. I reflected that although it was frustrating for me to have wasted my time with the visits, it was more important for patients at the hospital to feel held in mind, and

therefore more important that our meetings were cancelled in favour of clinic time.

21.2. Discontinuing CAMHS Recruitment

Despite all of the support that I got from the large majority of teams that I approached, the final research project had to be altered from the intended study. The original design included three groups; the diabetes group, the control group, and also a group recruited through CAMHS, siblings of children with a mental health difficulty. All ethical approval had been granted and teams approached for this three-group design. However, it became apparent quite quickly that although recruitment for the control and diabetes groups was slow, no CAMHS participants were being recruited at all.

It was at this stage that I recognised the difficulties with being on the periphery of a system, asking people in already busy services to give me additional help by giving out more information sheets to families on their caseloads. At times it felt quite uncomfortable putting such large demands on these clinicians, most of whom barely knew me, especially at a time of considerable service change, with most CAMHS services transferring to the Choice and Partnership Approach (CAPA) system at the time of recruitment. At one team meeting I recall the clinicians seeming rather defensive, having clearly worked hard to get some participants but families simply not being suitable or willing. It also felt as though there was some aggression being directed towards me, which at first felt quite personal. However, using

elements of systems theory (Mikesell, Lusterman, & McDaniel, 1995), I reflected that through placing more demands on the CAMHS team at a time when it was already undergoing much change and flux, further instability in this system was likely to be created. This helped me to see that although an element of aggression or frustration was perhaps being directed at me, these may have been emotions that were being strongly felt within the whole team at that time given the change to CAPA, and were simply being enacted in front of me. I feel this incident gave me first-hand experience of the way that what is happening within any system can be influenced by, but can also influence, individuals within and on the periphery of that system. These reflections helpfully enabled me to acknowledge these emotions, but then to metaphorically leave them in the room when I left.

After some months attending such meetings and pursuing these services, however, it was decided to stop attempts to recruit this group, and focus instead on the diabetes and control groups only, where recruitment was a little steadier. Although hugely disappointing, this part of the process certainly made me more aware of my own strengths. It was disheartening to have to change the focus of my project, especially after dedicating so much time and effort to the planning and preparations, but I learnt that I could cope with such set-backs and continue forward despite unexpected challenges. It also undoubtedly helped having my supervision team around me, as a positive, protective system.

From follow-up discussions with CAMHS clinicians, I discovered that the main reason for lack of recruitment was that families who were approached tended to feel they had too many demands already on their time, and that the sibling with a mental health difficulty tended to require much time and attention, often with regular appointments and issues arising at home and school. As above, this left me with a strong feeling of inequality, that these families would be left out of the research and their views would not be represented. However, it also highlighted the importance of the research I was doing, and left me feeling even more curious to find out about the experiences of siblings in these families. It seemed that there was perhaps something qualitatively different about the experiences of these families as compared to the diabetes group families, or it may simply have been due to the fact that the families in the diabetes group were used to taking part in research as they were largely recruited from a teaching and research hospital. Either way, the experience emphasised the importance of this field of research, and the importance of the perhaps “invisible” children (Gray, Robinson, & Seddon, 2008) in these families getting the support that they may need, for example through services such as Young Carers. This may be an area of research that I pursue in the future.

22. Impact of the Research on My Clinical Practice

I reflected clinically on many aspects of the research process. Overall, I believe it has heightened my wish to work with people not only to relieve symptoms but also to build resilience, using a positive psychology framework

(Seligman, 2002). As psychologists we are aware that once negative symptoms have lessened, people do not automatically develop new strengths and have easier lives. However, we are often restrained by limited time and resources, preventing much preventative, resilience-building work from being completed, possibly leading to the revolving door phenomenon, with clients being re-referred once symptoms return. The process of carrying out this research and writing the thesis has brought this issue to the forefront of my attention, and I hope to always practise “positive therapy” (Joseph & Linley, 2006) wherever possible.

Other influences on my clinical practice that were developed from this research, came from the experiences of being within new teams and systems, such as the example above of the importance of holding clients in mind. When gathering data, for instance, I noticed how comfortable I felt with certain families, and that often those were the families whose compositions were similar to my own experiences growing up, being a younger sister with an older brother in a two-parent family. I reflected that often these were the families with whom I felt most at ease, perhaps due to the familiarity and similarities. Clinically, therefore, this experience has been helpful, raising my awareness of my own preferences and prejudices, and the impact that this could have on the dynamics in the room if working with a family.

23. Reflections on My Own Systems

It was interesting, then, through the course of this research, to find myself amongst all of these different systems of hospitals, teams and families, somewhat reflecting Bronfenbrenner's (1986) ecological systems theory. As well as being an essential course requirement, I was able to enjoy the research experience and felt hugely privileged to be given the opportunity. I feel the experience helped me to develop both personally and professionally, both in research and clinical fields, as well as bringing these two together, thinking about the role of research and theory within clinical practice. I feel I will be able to use this experience of having worked in so many interlinked systems, to further develop my strengths on both a personal and professional level.

Not only did this research process make me feel extremely privileged to be in a position to carry out such interesting research and meet such remarkable families, however, it also made me reflect on my own family background. I have always felt lucky to come from a supportive and resilient family, and this research emphasised that further. Seeing children over the broad age range from 11 to 17 years also prompted me to think about my own development throughout childhood and adolescence, within the context of my family system. I think these reflections in turn helped me to further engage in the topic, and kept my enthusiasm alight over the course of the two to three years.

24. Summary

Apart from completing the research, data collection, analyses and write-up, the whole experience of creating this thesis from start to finish has provided me with many opportunities for reflection, and personal and professional development. Some of these opportunities were somewhat anticipated, but others were new and unexpected. The process has been extremely varied, and I have had the good fortune to meet many people, teams and families from whom I have learnt a lot. It has also given me the chance to test my own personal strengths and resources, and has been an invaluable experience that I will look back on positively. I look forward to continuing with my research interests in my future career.

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07.04.10 Version 1

Parent Cover Letter

Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street

DATE

Dear Parent,

This letter is being sent to you on my behalf from _____. (service / school), as they have identified you as a potential family who meet the criteria for my doctoral research into childhood well-being and resilience.

They have not given me any of your details and that is why I am not contacting you directly. I would be extremely grateful if you would take a few moments to read the enclosed information sheets and contact me should you have any queries about the study. If you think you might be interested in allowing your child to participate, please complete and return the enclosed "Consent to be contacted" form in the envelope provided, if possible within 2 weeks of receiving this letter. Returning this form **does not** mean that you will have to take part in the study, it simply means that I will contact you to talk to you about whether you and your child might want to take part.

I hope that you will be happy to return the form so that I can contact you, but do not hesitate to contact me before returning the form should you have any questions or hesitations.

Many thanks for your time, it really is greatly appreciated.

Yours Faithfully,

Becky Clay
Trainee Clinical Psychologist

26.05.10 (Version 2) **Information Sheet for Parents (Control Group)**

Title of research project: Investigating resilience in siblings of children with a health condition.

Researcher: Becky Clay, Trainee Clinical Psychologist
(Supervised by Dr Sarah Kent and Dr Eve Knight, Clinical Psychologists)

I am training to be a clinical psychologist within the Coventry and Warwickshire Partnership NHS Trust, with affiliation to both Coventry University and Warwick University. As part of my doctoral training I am carrying out research which will form part of my final thesis. The area I have chosen to research is resilience in children who have a sibling with a mental/emotional or physical health condition. This means that I also need to do the same research with children who have a sibling who require no specialist health services, to comprise a control group. This allows comparison of the groups to make the research stronger and more robust. It is this control group that I am hoping to recruit through the school.

What is the purpose of the research?

The purpose of this research is to investigate resilience in children who have a sibling with a physical health condition, a mental/emotional health difficulty, or a sibling with no health conditions (control group). Previous research has shown that resilience in children can be a good predictor of their psychological well-being. I am interested to find out whether having a sibling with a mental or physical health condition may have some positive effects on children, perhaps increasing their level of resilience, which may in turn aid their psychological well-being.

Previous research has shown that physical or mental illness in one family member can have an impact on the other members of the family, but has focussed largely on parent-child relationships. Some sibling studies have now been conducted, but these have focussed largely on the negative effects on behaviour and emotional health, rather than positive effects such as resilience.

By studying resilience in children who have a sibling with a health condition, and comparing this to the young people in the control group, I hope to be able to inform children's health services of the need to consider the well-being of their patients' siblings, in order to promote this and prevent some of the negative effects that have previously been found.

Why has my child been chosen?

Your child is part of a random sample and may fit the criteria for the control group of this study. I am looking for children and young people aged 11 to 17 years (inclusive), who have a sibling who does not have regular appointments with specialist health services. I hope to include 21 children who have a sibling with a mental health difficulty, 21 who have a sibling with a

physical health condition, and 21 who have a sibling currently requiring no specialist health services for the control group. Of course, if your child meets the criteria for one of the other two groups rather than the control group, they are welcome to participate in that group.

Does my child have to take part?

It is up to you and your child to decide whether he or she would like to participate. If you decide that your child may participate, I would ask you and your child to sign a consent form. However, even once you have signed these consent forms, you still have the right to withdraw from the study at any time. You would not need to give a reason. If you have more than one child aged 11 to 17 years, it is possible that each child could participate in the study.

What happens to my child if he/she takes part?

If you and your child decide you might wish to take part, simply send me the enclosed Consent to be Contacted form. I will then contact you to discuss the research further and answer any questions you have. If agreed, I will then arrange to meet with your child for approximately 50 minutes in a location and at a time convenient to you both. Unfortunately I will be unable to reimburse any travel costs that you incur. However, home visits may be possible.

What will my child have to do?

Your child will be asked to complete some brief tasks and questionnaires, which include some puzzles, a reasoning task, and questions regarding how they see themselves and the family. You will also be asked to complete a short questionnaire about your child and his/her sibling which will help me to ensure that the study meets all necessary criteria.

What are the possible disadvantages and risks of taking part?

I do not anticipate that there will be any risk of distress to your child. The tasks are designed to be enjoyable as far as possible. However, should your child become distressed the session will be stopped and appropriate support offered. I will stop all tasks at your child's request at any time.

What are the possible benefits of taking part?

I do not anticipate that there will be any specific personal benefits in taking part, but I do hope that your child will enjoy the varied questionnaires and tasks. The information gained from this research will develop current understanding of the effects of having a sibling with a health condition, which I hope will aid services in providing information, support and health promotion to patients and their families.

What happens when the study is finished?

After I have finished collecting all the data, the data will be analysed and written up anonymously for my thesis and for scientific journals and presentations.

I will also ask you (on the consent form) to tick a box if you would like a summary report of the results. If you request a report, this will be sent to you once the study is completed. I will not contact you again, but please do not hesitate to contact me if you would like any further information.

Will my child's participation and data be kept confidential?

All information which is collected about and from your child will be kept **strictly confidential**. None of the reports that will be written as a result of this research will include any identifying details of any of the children that participate. No individuals will be identified in any way. Data will be stored safely for five years and will then be destroyed.

However, in the rare instance that you or your child tell me something that puts somebody at risk, I will be obliged to inform my supervisors of this.

Who has reviewed this research?

The research has been reviewed by the ethics committee at Coventry University and by NHS ethics and research committees.

Who can I contact for further information?

If you have any further questions or concerns, please do not hesitate to contact the researcher:

Becky Clay
Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

Email: clayr@uni.coventry.ac.uk

Tel: 02476 888328 (to leave a message with the office for me to call you back)

If you have any concerns or complaints that you do not wish to discuss with the researcher, please contact either:

Complaints

Registry Office
Coventry University
Priory Street
Coventry
CV1 5FB

Tel 02476 887 688

Pro-Vice-Chancellor

Professor Ian Marshall
Room AB124
Coventry University
Priory Street
Coventry, CV1 5FB

Tel: 02476 795294

Supervisors:

Dr Eve Knight and Dr Sarah Kent
Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 02476 888328

Many thanks for taking the time to read this information. I hope you feel happy to allow your child to participate in the research.

26.05.10 (Version 2) **Information Sheet for Parents (Diabetes Group)**

Title of research project: Investigating resilience in siblings of children with a health condition.

Researcher: Becky Clay, Trainee Clinical Psychologist
(Supervised by Dr Sarah Kent and Dr Eve Knight, Clinical Psychologists)

I am training to be a clinical psychologist within the Coventry and Warwickshire Partnership NHS Trust, with affiliation to both Coventry University and Warwick University. As part of my doctoral training I am carrying out research which will form part of my final thesis. The area I have chosen to research is resilience in children who have a sibling with a mental/emotional health difficulty or physical health condition requiring specialist health services.

What is the purpose of the research?

The purpose of this research is to investigate resilience in children who have a sibling with a physical health condition or a mental/emotional health difficulty. Previous research has shown that resilience in children can be a good predictor of their psychological well-being. I am interested to find out whether having a sibling with a mental or physical health condition may have some positive effects on children, perhaps increasing their level of resilience, which may in turn aid their psychological well-being.

Previous research has shown that physical or mental illness in one family member can have an impact on the other members of the family, but has focussed largely on parent-child relationships. Some sibling studies have now been conducted, but these have focussed largely on the negative effects on behaviour and emotional health, rather than positive effects such as resilience. It may be possible that children who have a sibling with a mental or physical health condition might develop a higher level of resilience than those whose siblings require little extra support or attention.

By studying resilience in children who have a sibling with a health condition, I hope to be able to inform children's health services of the need to consider the well-being of their clients' siblings, in order to promote this and prevent some of the negative effects that have previously been found.

Why has my child been chosen?

Your child has been identified as fitting the criteria of this study. I am looking for children and young people aged 11 to 17 years who have a sibling with either a physical health condition or a mental/emotional health difficulty. I hope to include 21 children who have a sibling with a mental health difficulty, 21 who have a sibling with a physical health condition, and 21 who have a sibling currently requiring no specialist health services for the control group.

Does my child have to take part?

It is up to you and your child to decide whether he or she would like to participate. If you decide that your child may participate, I would ask you and your child to sign a consent form (you will be given a copy of the signed consent forms). However, even once you have signed these consent forms, you still have the right to withdraw from the study at any time. You would not need to give a reason and this would not affect any services your child receives.

What happens to my child if he/she takes part?

If you and your child decide you might wish to take part, simply send me the enclosed Consent to be Contacted form. I will then contact you to discuss the research further and answer any questions you have. If agreed, I will then arrange to meet with your child for approximately 50 minutes in a location and at a time convenient to you both. Unfortunately, I will be unable to reimburse any travel costs that you incur. However, home visits may be possible.

What will my child have to do?

Your child will be asked to complete some brief tasks and questionnaires, which include some puzzles, a reasoning task, and questions regarding how they see themselves and the family. You will also be asked to complete a short questionnaire about your child and his/her sibling which will help me to ensure that the study meets all necessary criteria.

What are the possible disadvantages and risks of taking part?

I do not anticipate that there will be any risk of distress to your child. The tasks are designed to be enjoyable as far as possible. However, should your child become distressed the session will be stopped and appropriate support offered. I will stop all tasks at your child's request at any time.

What are the possible benefits of taking part?

I do not anticipate that there will be any specific personal benefits in taking part, but I do hope that your child will enjoy the varied questionnaires and tasks. The information gained from this research will develop current understanding of the effects of having a sibling with a health condition, which I hope will aid services in providing information, support and health promotion to patients and their families.

What happens when the study is finished?

After I have finished collecting all the data, the data will be analysed and written up anonymously for my thesis and for scientific journals and presentations.

I will also ask you (on the consent form) to tick a box if you would like a summary report of the results. If you request a report, this will be sent to you once the study is completed. I will not contact you again, but please do not hesitate to contact me if you would like any further information.

Will my child's participation and data be kept confidential?

All information which is collected about and from your child will be kept **strictly confidential**. None of the reports that will be written as a result of this research will include any identifying details of any of the children that participate. No individuals will be identified in any way. Data will be stored safely for five years and will then be destroyed.

However, in the rare instance that you or your child tell me something that puts somebody at risk, I will be obliged to inform my supervisors of this.

Who has reviewed this research?

The research has been reviewed by the ethics committee at Coventry University and by NHS ethics and research committees.

Who can I contact for further information?

If you have any further questions or concerns, please do not hesitate to contact the researcher:

Becky Clay
Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
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Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 02476 888328

Many thanks for taking the time to read this information. I hope you feel happy to allow your child to participate in the research.

Participant Information Sheet (Control Group)

My name is Becky Clay, I am training to be a clinical psychologist in the Coventry and Warwickshire area. I am conducting a research project to find out about people's strengths, and what helps people to feel good about themselves and their life.

What is the project all about?

I want to find out what children and young people are like who have a brother or sister with a health condition. This means that I need to talk to young people who have a sibling with a health condition, but I also need to talk to young people who have a sibling who *does not* have a health condition, to be a "control group". Having a control group is important to make the research findings stronger, by comparing the groups.

Why have I been asked to take part?

You have been asked to take part because you are between 11 and 17 years old and you have a sibling who does not have a health condition that requires regular contact with specialist services. This means that you would be a member of the control group.

What would I have to do?

If you decide that you want to take part, I will meet with you for about 50 minutes and ask you some questions about yourself and your family. We will also do some puzzles. But don't worry, this is not like work or tests. There are no right or wrong answers, I just want to find out a bit about you.

Who would have access to the tasks and puzzles that I do?

Anything you do or say in the research meeting would remain confidential, meaning that only me and my two research supervisors will have access to this information. However, if you tell me anything that I think might mean that somebody is at risk, I may need to inform other people who could help.

What if I want to know more?

If you want any more information about my research project, you can email or call me, or ask a parent/guardian to contact me.

Becky Clay

Tel: 02476 888328 (to leave a message with the office for me to call you back)

Email: clayr@uni.coventry.ac.uk

Thank you for taking the time to read this ☺

26.05.10 (Version 2)

Participant Information Sheet

My name is Becky Clay, I am training to be a clinical psychologist in the Coventry and Warwickshire area. I am conducting a research project to find out about people's strengths, and what helps people to feel good about themselves and their life.

What is the project all about?

I want to find out what children and young people are like who have a brother or sister with a health condition requiring specialist services.

Why have I been asked to take part?

You have been asked to take part because you are between 11 and 17 years old and you have a sibling who accesses specialist health services.

What would I have to do?

If you decide that you want to take part, I will meet with you for about 50 minutes and ask you some questions about yourself and your family. We will also do some puzzles. But don't worry, this is not like work or tests. There are no right or wrong answers, I just want to find out a bit about you.

Who would have access to the tasks and puzzles that I do?

Anything you do or say in the research meeting would remain confidential, meaning that only me and my two research supervisors will have access to this information. However, if you tell me anything that I think might mean that somebody is at risk, I may need to inform other people who could help.

What if I want to know more?

If you want any more information about my research project, you can email or call me, or ask a parent/guardian to contact me.

Becky Clay

Tel: 02476 888328 (to leave a message with the office for me to call you back)

Email: clayr@uni.coventry.ac.uk

Thank you for taking the time to read this ☺

26.05.10 (Version 2)

Consent to be Contacted Form (V1: 07.04.10)

Title of research project: Investigating resilience in siblings of children accessing specialist health services.

Researcher: Becky Clay, Trainee Clinical Psychologist
(Supervised by Dr Sarah Kent and Dr Eve Knight, Clinical Psychologists)

I agree to be contacted by Becky Clay to receive further information about this research project.

☐

Name: _____.

Phone: _____ (best days/times to call are: _____)

Email: _____.

Postal address: _____.

_____.

_____.

By consenting to be contacted you DO NOT consent to participate, but only to be contacted by Becky Clay.

.....
Name of parent/Guardian

.....
Date

.....
Signature

Thank You

Please either return this form to the department you received it from, or directly to Becky Clay, Clinical Psychology Doctorate, Faculty of Health & Life Sciences, Coventry University, Priory Street, Coventry, CV1 5FB, in the envelope provided.

Parent Consent Form

Title of research project: Investigating resilience in siblings of children accessing specialist health services.

Researcher: Becky Clay, Trainee Clinical Psychologist
(Supervised by Dr Sarah Kent and Dr Eve Knight, Clinical Psychologists)

1) I have read and understood the information sheet provided regarding this project

☐

2) I have had the opportunity to ask questions and raise any concerns

☐

3) I understand that participation in the study is voluntary and that we can withdraw from the study at any time without our treatment by services being affected

☐

4) I agree for my child to participate in this study

☐

5) I have spoken to my child about this study

☐

Child's name _____ Child's age _____.

Name of Parent/Guardian _____.

Parent/Guardian's Signature _____ Date: _____.

I would like to receive a summary report of this research ☐ (please tick)

Please provide your address if you require a summary report:

Address: _____.

Participant Consent Form

Would you like to take part in this project?

☐

Yes, I would like to take part

☐

No thanks, I would not like to take part

Remember, if you say yes now you can still change your mind later!

Participant's name _____.

Researcher's name _____.

Date _____.

Here is a list of things that happen to people and that people think, feel, or do. Read each sentence carefully, and circle the *one* answer (Never, Rarely, Sometimes, Often, or Almost Always) that tells about you best. THERE ARE NO RIGHT OR WRONG ANSWERS.

	0	1	2	3	4
1. Life is fair.	Never	Rarely	Sometimes	Often	Almost Always
2. I can make good things happen.	Never	Rarely	Sometimes	Often	Almost Always
3. I can get the things I need.	Never	Rarely	Sometimes	Often	Almost Always
4. I can control what happens to me.	Never	Rarely	Sometimes	Often	Almost Always
5. I do things well.	Never	Rarely	Sometimes	Often	Almost Always
6. I am good at fixing things.	Never	Rarely	Sometimes	Often	Almost Always
7. I am good at figuring things out.	Never	Rarely	Sometimes	Often	Almost Always
8. I make good decisions.	Never	Rarely	Sometimes	Often	Almost Always
9. I can adjust when plans change.	Never	Rarely	Sometimes	Often	Almost Always
10. I can get past problems in my way.	Never	Rarely	Sometimes	Often	Almost Always
11. If I have a problem, I can solve it.	Never	Rarely	Sometimes	Often	Almost Always
12. If I try hard, it makes a difference.	Never	Rarely	Sometimes	Often	Almost Always
13. If at first I don't succeed, I will keep on trying.	Never	Rarely	Sometimes	Often	Almost Always
14. I can think of more than one way to solve a problem.	Never	Rarely	Sometimes	Often	Almost Always
15. I can learn from my mistakes.	Never	Rarely	Sometimes	Often	Almost Always
16. I can ask for help when I need to.	Never	Rarely	Sometimes	Often	Almost Always
17. I can let others help me when I need to.	Never	Rarely	Sometimes	Often	Almost Always
18. Good things will happen to me.	Never	Rarely	Sometimes	Often	Almost Always
19. My life will be happy.	Never	Rarely	Sometimes	Often	Almost Always
20. No matter what happens, things will be all right.	Never	Rarely	Sometimes	Often	Almost Always

For *T* scores, see Table A.1.

TS

RS

Here is a list of things that happen to people and that people think, feel, or do. Read each sentence carefully, and circle the *one* answer (Never, Rarely, Sometimes, Often, or Almost Always) that tells about you best. THERE ARE NO RIGHT OR WRONG ANSWERS.

	0	1	2	3	4
1. I can meet new people easily.	Never	Rarely	Sometimes	Often	Almost Always
2. I can make friends easily.	Never	Rarely	Sometimes	Often	Almost Always
3. People like me.	Never	Rarely	Sometimes	Often	Almost Always
4. I feel calm with people.	Never	Rarely	Sometimes	Often	Almost Always
5. I have a good friend.	Never	Rarely	Sometimes	Often	Almost Always
6. I like people.	Never	Rarely	Sometimes	Often	Almost Always
7. I spend time with my friends.	Never	Rarely	Sometimes	Often	Almost Always
8. Other people treat me well.	Never	Rarely	Sometimes	Often	Almost Always
9. I can trust others.	Never	Rarely	Sometimes	Often	Almost Always
10. I can let others see my real feelings.	Never	Rarely	Sometimes	Often	Almost Always
11. I can calmly tell others that I don't agree with them.	Never	Rarely	Sometimes	Often	Almost Always
12. I can make up with friends after a fight.	Never	Rarely	Sometimes	Often	Almost Always
13. I can forgive my parent(s) if they upset me.	Never	Rarely	Sometimes	Often	Almost Always
14. If people let me down, I can forgive them.	Never	Rarely	Sometimes	Often	Almost Always
15. I can depend on people to treat me fairly.	Never	Rarely	Sometimes	Often	Almost Always
16. I can depend on those closest to me to do the right thing.	Never	Rarely	Sometimes	Often	Almost Always
17. I can calmly tell a friend if he or she does something that hurts me.	Never	Rarely	Sometimes	Often	Almost Always
18. If something bad happens, I can ask my friends for help.	Never	Rarely	Sometimes	Often	Almost Always
19. If something bad happens, I can ask my parent(s) for help.	Never	Rarely	Sometimes	Often	Almost Always
20. There are people who will help me if something bad happens.	Never	Rarely	Sometimes	Often	Almost Always
21. If I get upset or angry, there is someone I can talk to.	Never	Rarely	Sometimes	Often	Almost Always
22. There are people who love and care about me.	Never	Rarely	Sometimes	Often	Almost Always
23. People know who I really am.	Never	Rarely	Sometimes	Often	Almost Always
24. People accept me for who I really am.	Never	Rarely	Sometimes	Often	Almost Always

For T scores, see Table A.1.

TS

RS

Here is a list of things that happen to people and that people think, feel, or do. Read each sentence carefully, and circle the *one* answer (Never, Rarely, Sometimes, Often, or Almost Always) that tells about you best. THERE ARE NO RIGHT OR WRONG ANSWERS.

	0	1	2	3	4
1. It is easy for me to get upset.	Never	Rarely	Sometimes	Often	Almost Always
2. People say that I am easy to upset.	Never	Rarely	Sometimes	Often	Almost Always
3. I strike back when someone upsets me.	Never	Rarely	Sometimes	Often	Almost Always
4. I get very upset when things don't go my way.	Never	Rarely	Sometimes	Often	Almost Always
5. I get very upset when people don't like me.	Never	Rarely	Sometimes	Often	Almost Always
6. I can get so upset that I can't stand how I feel.	Never	Rarely	Sometimes	Often	Almost Always
7. I get so upset that I lose control.	Never	Rarely	Sometimes	Often	Almost Always
8. When I get upset, I don't think clearly.	Never	Rarely	Sometimes	Often	Almost Always
9. When I get upset, I react without thinking.	Never	Rarely	Sometimes	Often	Almost Always
10. When I get upset, I stay upset for about one hour.	Never	Rarely	Sometimes	Often	Almost Always
11. When I get upset, I stay upset for several hours.	Never	Rarely	Sometimes	Often	Almost Always
12. When I get upset, I stay upset for the whole day.	Never	Rarely	Sometimes	Often	Almost Always
13. When I get upset, I stay upset for several days.	Never	Rarely	Sometimes	Often	Almost Always
14. When I am upset, I make mistakes.	Never	Rarely	Sometimes	Often	Almost Always
15. When I am upset, I do the wrong thing.	Never	Rarely	Sometimes	Often	Almost Always
16. When I am upset, I get into trouble.	Never	Rarely	Sometimes	Often	Almost Always
17. When I am upset, I do things that I later feel bad about.	Never	Rarely	Sometimes	Often	Almost Always
18. When I am upset, I hurt myself.	Never	Rarely	Sometimes	Often	Almost Always
19. When I am upset, I hurt someone.	Never	Rarely	Sometimes	Often	Almost Always
20. When I am upset, I get mixed-up.	Never	Rarely	Sometimes	Often	Almost Always

For T scores, see Table A.1.

TS

RS

Coopersmith Self-Esteem Inventory

Please mark each statement in the following way:

If the statement describes how you usually feel, put a (X) in the column, "*Like me*".

If the statement does not describe how you usually feel put a check (X) in the column "Unlike me".

There are no right or wrong answers.

	Like me	Unlike me
1 I spend a lot of time daydreaming.		
2 I'm pretty sure of myself.		
3 I often wish I were someone else.		
4 I'm easy to like.		
5 My parents and I have a lot of fun together.		
6 I never worry about anything.		
7 I find it very hard to talk in front of the class.		
8 I wish I were younger.		
9 There are lots of things about myself I'd change if I could.		
10 I can make up my mind without too much trouble.		
11 I'm a lot of fun to be with.		
12 I get upset easily at home.		
13 I always do the right thing.		
14 I'm proud of my school work.		
15 Someone always has to tell me what to do.		
16 It takes me a long time to get used to anything new.		
17 I'm often sorry for the things I do.		

- 18 I'm popular with kids my own age.
- 19 My parents usually consider my feelings.
- 20 I'm never unhappy.
- 21 I'm doing the best work that I can.
- 22 I give in very easily.
- 23 I can usually take care of myself.
- 24 I'm pretty happy.
- 25 I would rather play with children younger than me.
- 26 My parents expect too much of me.
- 27 I like everyone I know.
- 28 I like to be called on in class.
- 29 I understand myself.
- 30 It's pretty tough to be me.
- 31 Things are all mixed up in my life.
- 32 Kids usually follow my ideas.
- 33 No one pays much attention to me at home.
- 34 I never get scolded.
- 35 I'm not doing as well in school as I'd like to.
- 36 I can make up my mind and stick to it.
- 37 I really like being a boy-----girl.
- 38 I have a low opinion of myself.
- 39 I don't like to be with other people.
- 40 There are many times when I'd like to leave home.
- 41 I'm never shy.

[illegible]

42 I often feel upset in school.

43 I often feel ashamed of myself.

44 I'm not as nice looking as most people.

45 If I have something to say, I usually say it.

46 Kids pick on my very often.

47 My parents understand me.

48 I always tell the truth.

49 My teacher makes me feel I'm not good enough.

50 I don't care what happens to me.

51 I'm a failure.

52 I get upset easily when I am scolded.

53 Most people are better liked than I am.

54 I usually feel as if my parents are pushing me.

55 I always know what to say to people.

56 I often get discouraged in school.

57 Things usually don't bother me.

58 I can't be depended on.

[illegible]

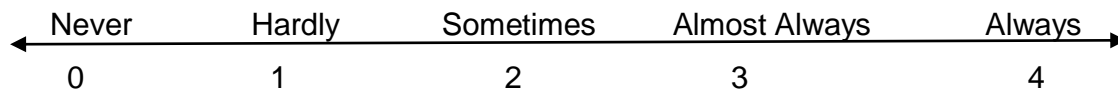
Participant Demographic Questionnaire

I would be grateful if you could complete these questions, so that I can ensure the study is fair.
The information will remain confidential.

1) How old are you?

_____.

2) Please rate the following five statements based on this scale:



a) When something is bothering me I can ask my family for help ☐

b) I like the way my family talks over things and shares problems
with me ☐

c) I like how my family lets me try new things I want to do ☐

d) I like what my family does/how they react when I feel angry
or happy ☐

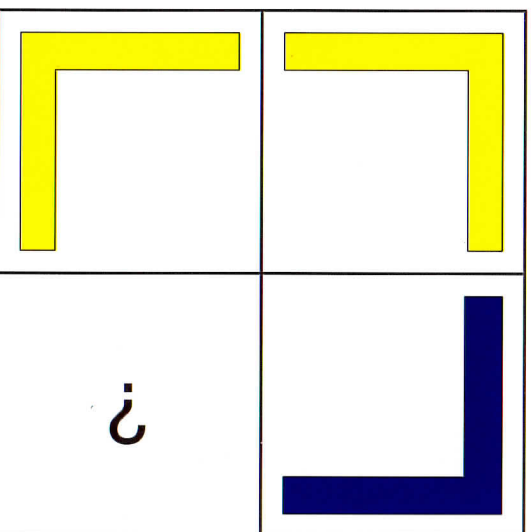
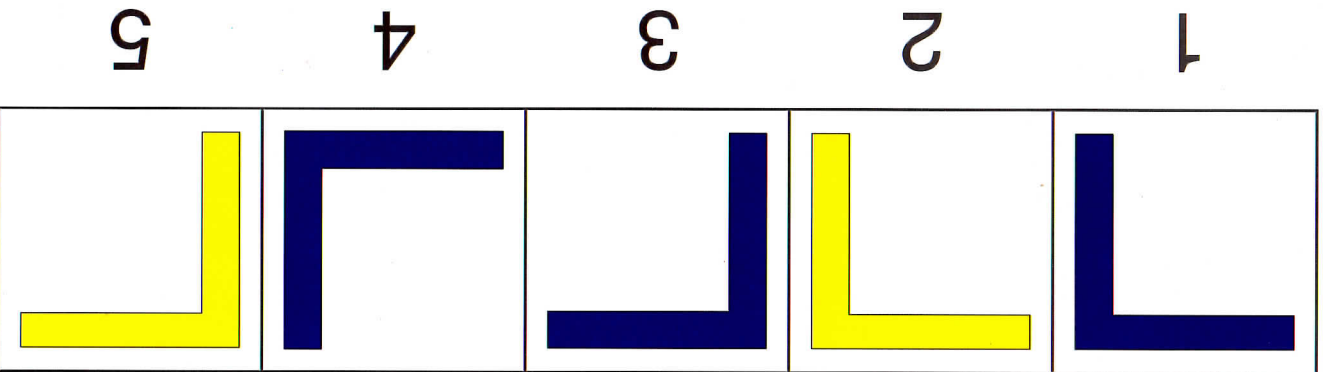
e) I like how my family and I share time together ☐

3) What do you think of having a brother and/or sister?

_____.

_____.

Thank you very much for your time and help with my study.



Parent Demographic Questionnaire (Control Group)

I would be grateful if you could complete the following questionnaire about your children. The information will remain confidential and will be used only to ensure the study is fair and meets the necessary criteria.

Please note:

- The child who **is taking part** in the study is referred to as your “**child**”.
- This child’s sibling who may **not** be taking part in the study is referred to as the “**sibling**”.

1) How old are your children?

Child (participant): _____ years

Sibling: _____ years

2) Are your children male or female?

Child (participant): _____.

Sibling: _____.

3) Does the child (participant) have any physical or mental health conditions or needs, or special learning needs? Please provide details.

_____.

4) Does your child have the same mother as his/her sibling?

_____.

5) Does your child have the same father as his/her sibling?

_____.

6) For how many years have the two children lived together?

_____.

7) How many days a week do the two children live in the same house?

_____.

Many thanks for your time. It is greatly appreciated.

(V1: 07.04.10)

Parent Demographic Questionnaire

I would be grateful if you could complete the following questionnaire about your children. The information will remain confidential and will be used only to ensure the study is fair and meets the necessary criteria.

Please note:

- Your child who **is taking part** in the study is referred to as the “**child**”.
- Your child who is **not** taking part in the study, who is affected by a physical health condition or mental/emotional health difficulty, is referred to as the “**sibling**”.

1) How old are your children?

Child (participant): _____ years

Sibling: _____ years

2) Are your children male or female?

Child (participant): _____.

Sibling: _____.

3) What is/are the sibling's diagnosis/diagnoses?

_____.

4) How often does the sibling see the specialist service regarding this condition?

_____.

5) Does your child (who is participating) have any physical or mental health conditions or needs, or special learning needs? Please provide details.

_____.

6) Does your child have the same mother and father as his/her sibling?

_____.

7) For how many years have the two children lived together?

_____.

8) How many days a week do the two children live in the same house?

_____.

Many thanks for your time. It is greatly appreciated.

(V1: 07.04.10)

TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

12 May 2010

Dear Sir/Madam

Researcher's name: Miss Sarah Rebecca Clay
Project Title: Investigating resilience in children who have a sibling with a health condition

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully



Professor Ian Marshall
Pro-Vice-Chancellor, Research

Enc





**National Research Ethics Service
The Black Country Research Ethics Committee**

Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW

Telephone: 01527 582531
:

28 June 2010

Miss (Sarah) Rebecca Clay
Trainee Clinical Psychologist
Coventry & Warwickshire Partnership NHS Trust
Clinical Psychology Doctorate
James Starley Building
Coventry University
CV1 5FB

Dear Miss Clay

Study Title: Investigating resilience in children who have a sibling
with a health condition
REC reference number: 10/H1202/39
Protocol number:

Thank you for your letter of 26 May 2010, responding to the Committee's request for further information on the above research and submitting revised documentation..

The further information has been considered on behalf of the Committee by the Vice Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV	Miss Clay	07 April 2010
Investigator CV	Supervisor - Dr Knight	
Protocol	1	07 April 2010
Service Cover letter	1	07 April 2010
Flyer for waiting areas	1	07 April 2010
REC application		07 April 2010
Covering Letter		07 April 2010
Letter from Sponsor		09 April 2010
Questionnaire: Coopersmith Self-Esteem Inventory		
Participant Information Sheet: Information Sheet for Participants [Group 1 & 2]	2	26 May 2010
Participant Consent Form: Participant Consent Form	1	07 April 2010
Participant Consent Form: Consent Form for parents	1	07 April 2010
Participant Consent Form: Consent Form for parents	1	07 April 2010
Response to Request for Further Information		
Response to Request for Further Information		26 May 2010
Participant Information Sheet: Information Sheet for Parents	1	07 April 2010
Participant Information Sheet		
Participant Information Sheet: Information Sheet for Services	1	07 April 2010
Participant Information Sheet		
Participant Information Sheet: Information Sheet for Parents [Group 1 & 2]	2	26 May 2010
Participant Information Sheet		
Participant Information Sheet		
Participant Information Sheet: Information for Participants [Control Group]	2	26 May 2010
Participant Consent Form: Consent Form for Services	1	07 April 2010
Participant Consent Form: Consent to be contact form	1	07 April 2010
Participant Consent Form: Consent to be contact form	1	07 April 2010
Questionnaire: RCSA		
Evidence of insurance or indemnity	AON	01 August 2009
Evidence of insurance or indemnity	QBE	01 August 2009
Marking Sheet		30 November 2009

Questionnaire: Demographic Questionnaire - Participant	1	07 April 2010
Questionnaire: Demographic Questionnaire - Parent [Groups 1 and 2]	1	07 April 2010
Questionnaire: Demographic Questionnaire - Parent [Group 3]	1	07 April 2010
Recruitment Flowchart	1	07 April 2010
was Manual		
Parent cover letter	1	07 April 2010
Participant and Parent de-brief information	1	07 April 2010
Appendix 15: Research Costings		16 September 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1202/39

Please quote this number on all correspondence

Yours sincerely



Anne McCullough [Mrs] *on behalf of*
Dr Jeff Neilson
Chair

Email: anne.mccullough@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers"



University Hospitals Coventry and Warwickshire



NHS Trust

Research & Development Department

R&D Services Manager: Ceri Jones - Tel: 024 7696 6196
R&D Divisional Finance Manager: Chris Moore - Tel: 024 7696 6198
Deputy Divisional Finance Manager: Reena Savani - Tel: 024 7696 6197
Deputy Divisional Finance Manager: Elena Edwards - Tel: 024 7696 6069
Assistant Research & Development Manager: Natasha Wileman - Tel: 02476 966197
Research & Development Assistant: Isabella Petrie - Tel: 02476 966202
Research & Development Assistant: Claire Bacon - Tel: 02476 964495

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcv.nhs.uk

6th July 2010

Miss (Sarah) Rebecca Clay
Trainee Clinical Psychologist
Coventry & Warwickshire Partnership NHS Trust
Clinical Psychology Doctorate
James Starley Building
Coventry University, CV1 5FB

Dear Rebecca

Re: Investigating Resilience in Children who have a Sibling with a Health Condition

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that such checks as are necessary have been carried out by your employer and that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. This letter confirms your right of access to conduct research through University Hospitals Coventry and Warwickshire NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 6th July 2010 and ends on 6th October 2011 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to University Hospitals Coventry and Warwickshire NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through University Hospitals Coventry and Warwickshire NHS Trust, you will remain accountable to your employer Coventry & Warwickshire Partnership Trust but you are required to follow the reasonable instructions of your nominated manager Heather Stirling in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any

Chief Executive: Malcolm Stamp CBE

Chairman: Philip Townshend

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Missed appointments' cost our hospitals nearly £4 million a year. Please help us reduce this by ensuring you attend yours or call 0800 252060 to change your date/time.

investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with University Hospitals Coventry and Warwickshire NHS Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with University Hospitals Coventry and Warwickshire NHS Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on University Hospitals Coventry and Warwickshire NHS Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

University Hospitals Coventry and Warwickshire NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Mrs. Ceri Jones
Research and Development Services Manager

cc: Heather Stirling, Consultant Paediatrician, University Hospital
Eve Knight, Clinical Psychology Doctorate, Coventry University

George Eliot Hospital

NHS Trust

22 December 2010

Rebecca Clay
Trainee Clinical Psychologist
Clinical Psychology Doctorate
Faculty of Health & Life Sciences
Coventry University
Priory Street
Coventry
CV1 5FB

George Eliot Hospital NHS Trust
College Street
NUNEATON
Warwickshire
CV10 7DJ
Direct Line: 024 7615 3670
Email: shelley.lapper@geh.nhs.uk

Dear Rebecca

Re: Investigating resilience in children who have a sibling with a health condition
MREC: 10/H1202/39

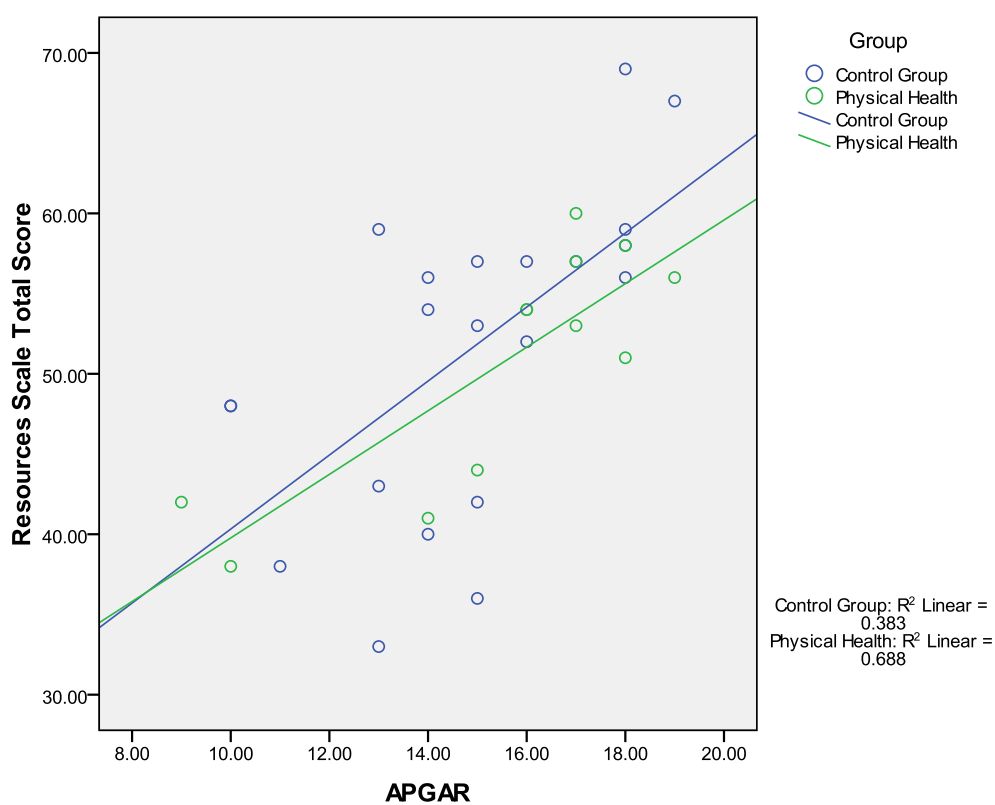
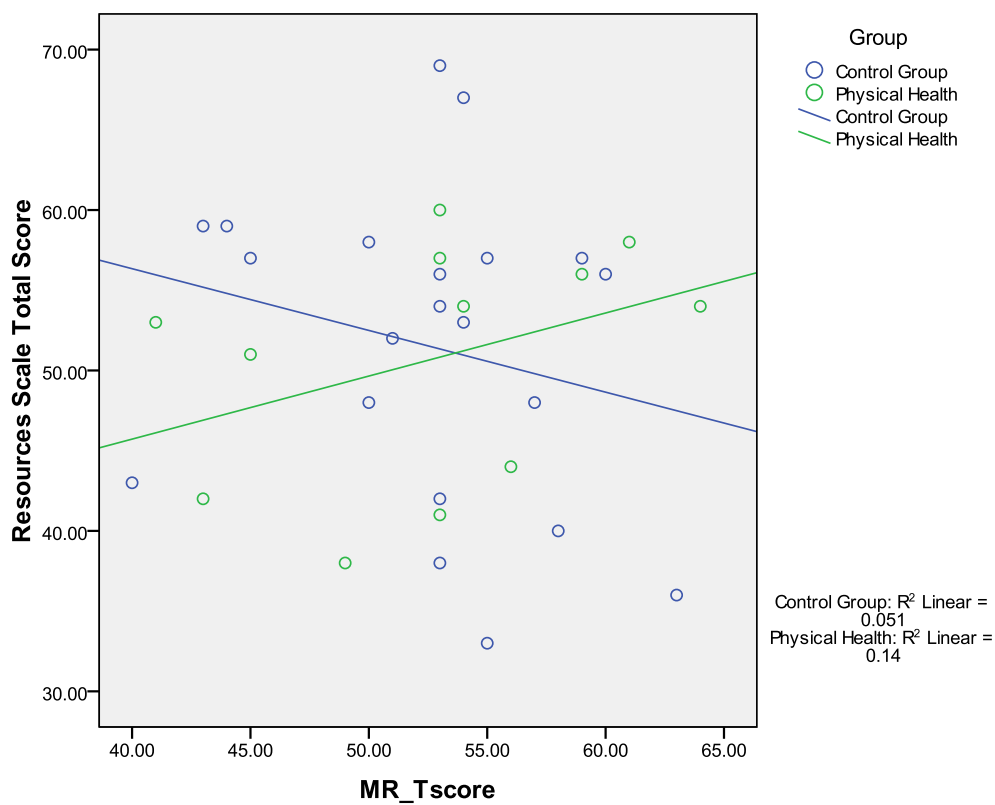
I am pleased to confirm that George Eliot Hospital NHS Trust has reviewed the above project and agrees to act a patient identification centre (PIC) in this research. Please note the Trust does not provide indemnity for this research.

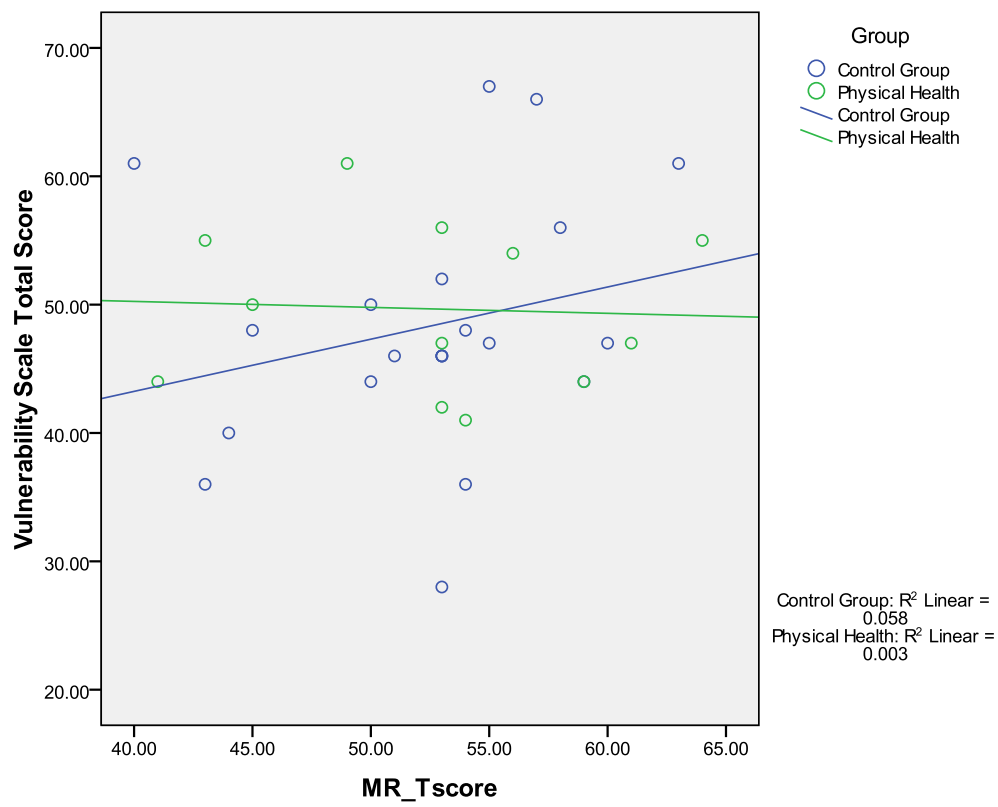
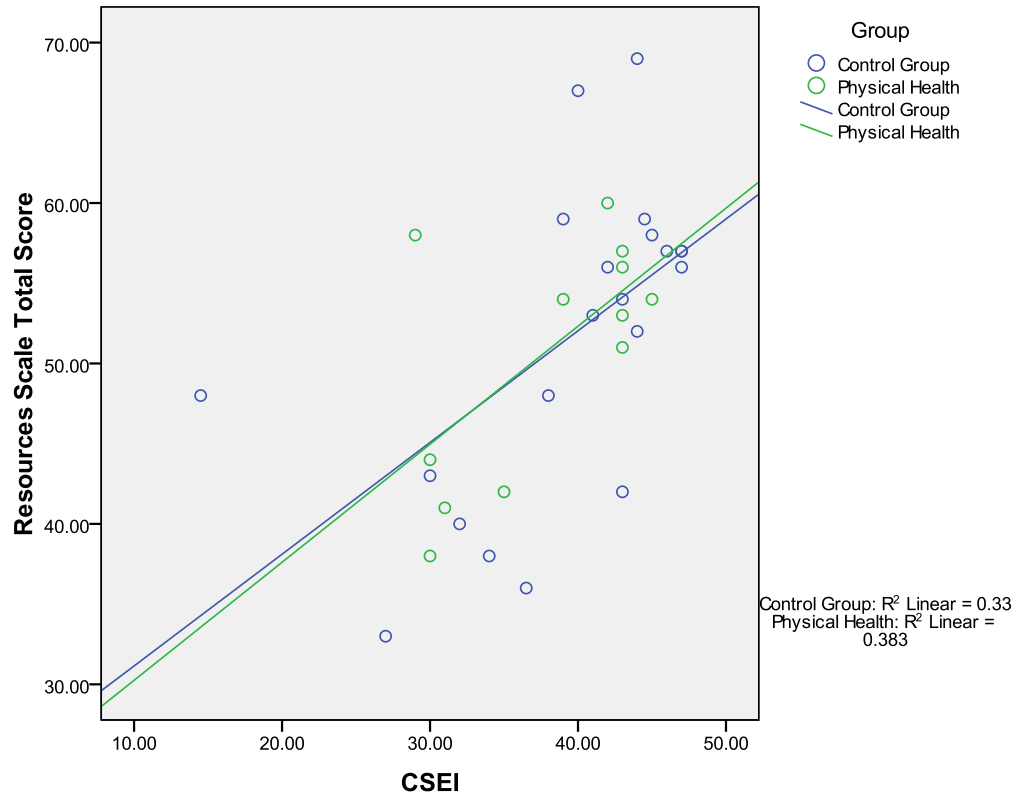
If you have any queries relating to R&D approval at George Eliot Hospital NHS Trust, please do not hesitate to contact me.

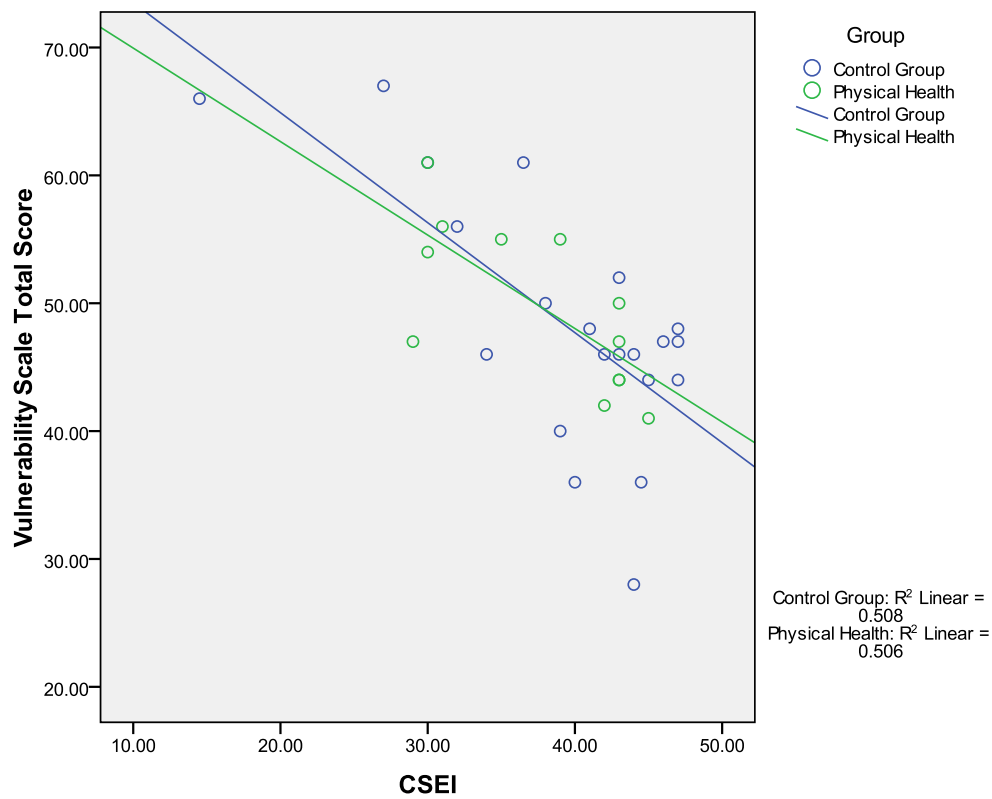
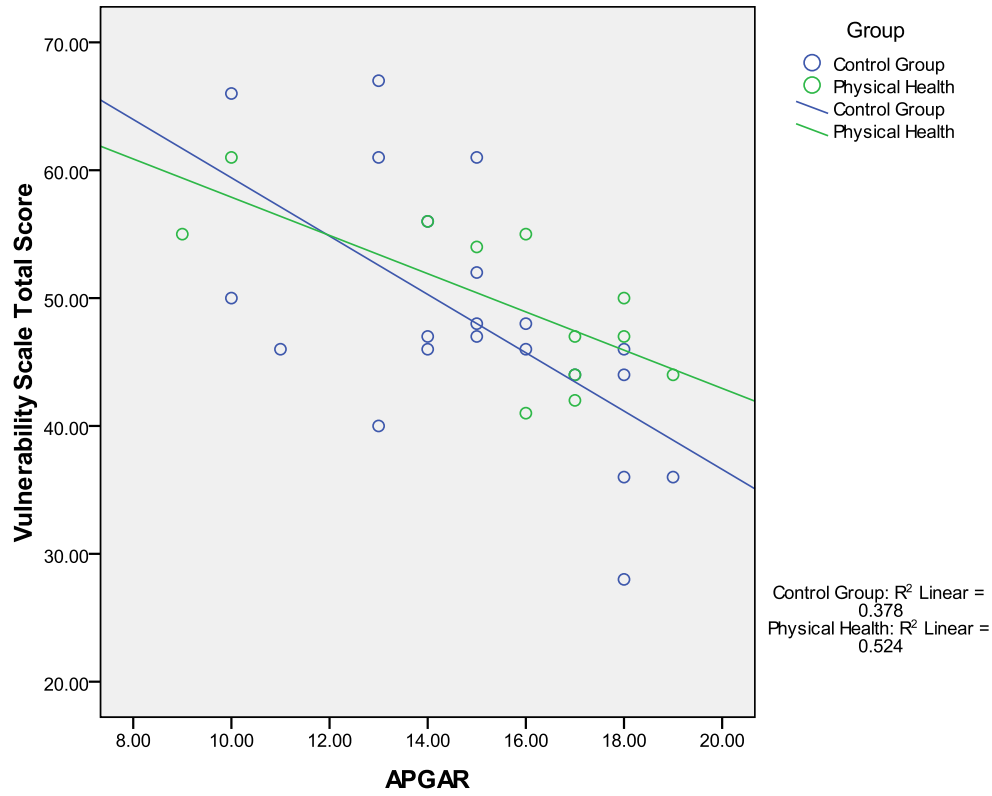
Yours sincerely

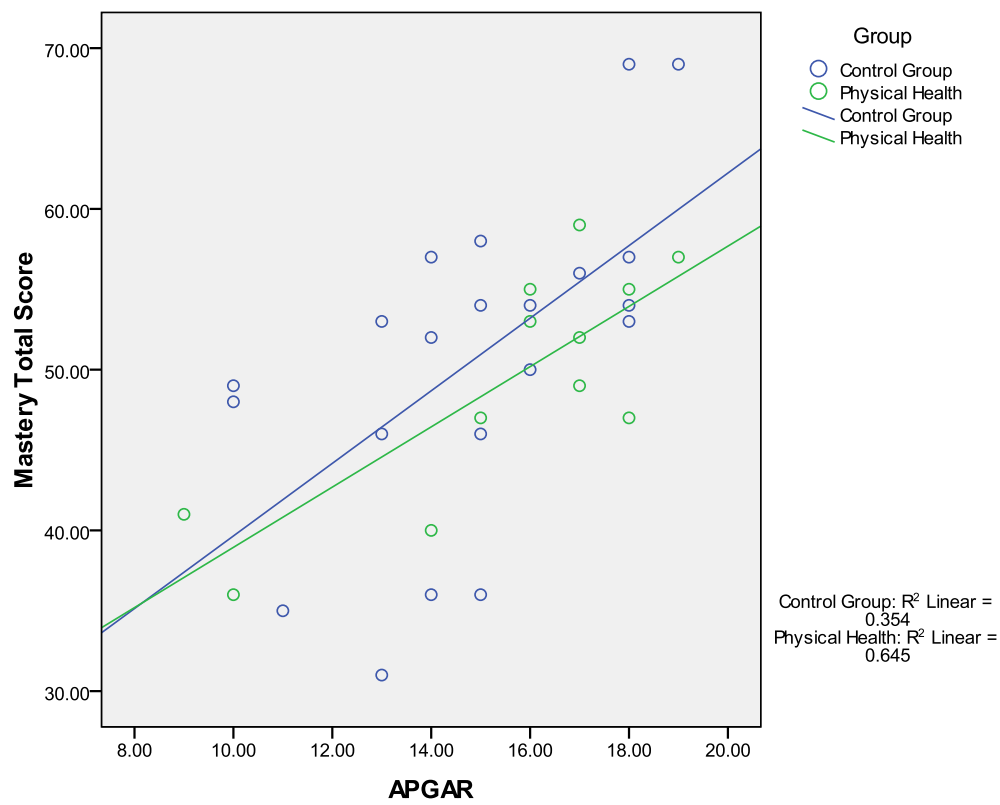
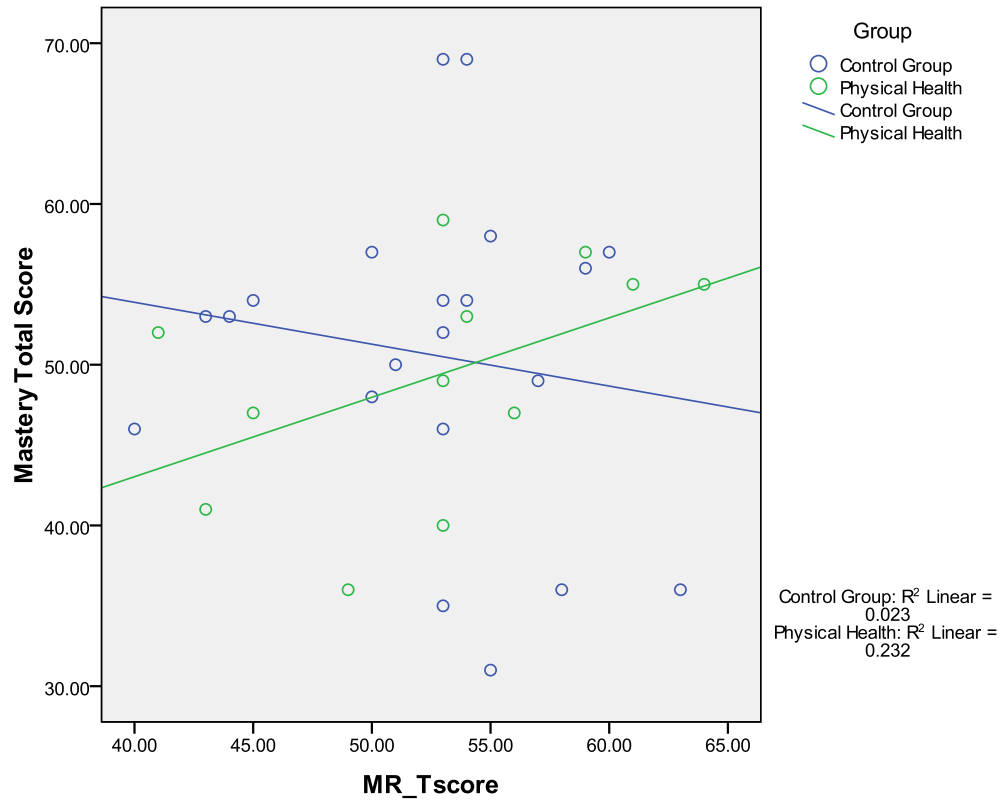


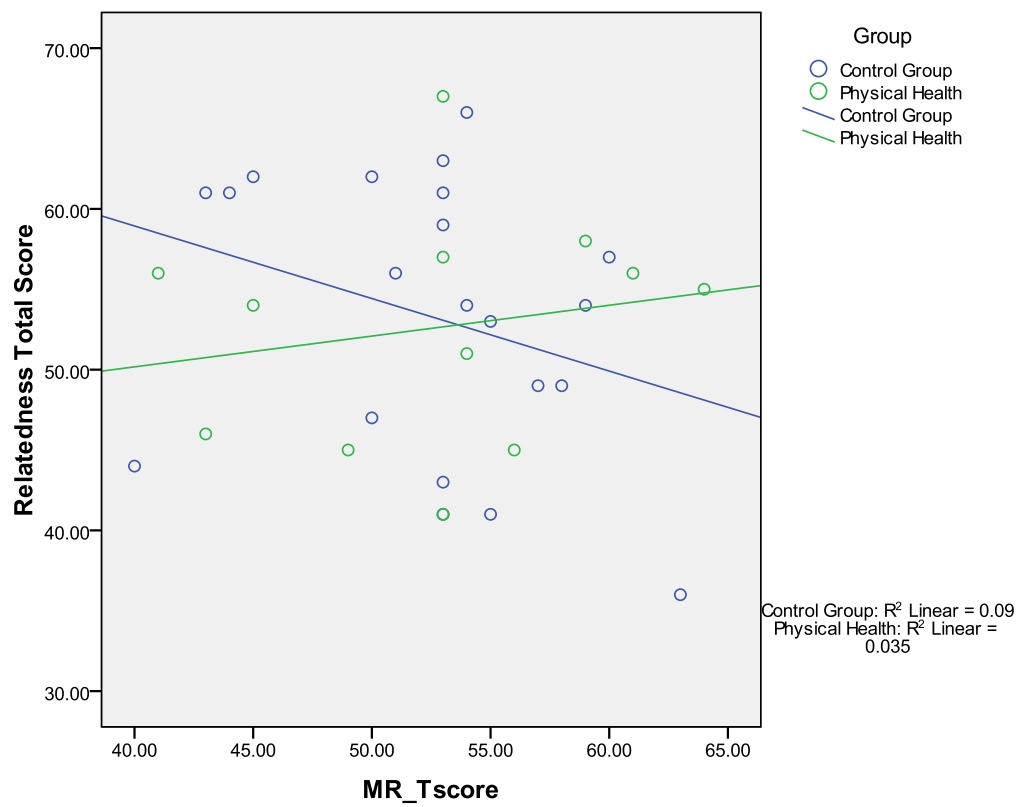
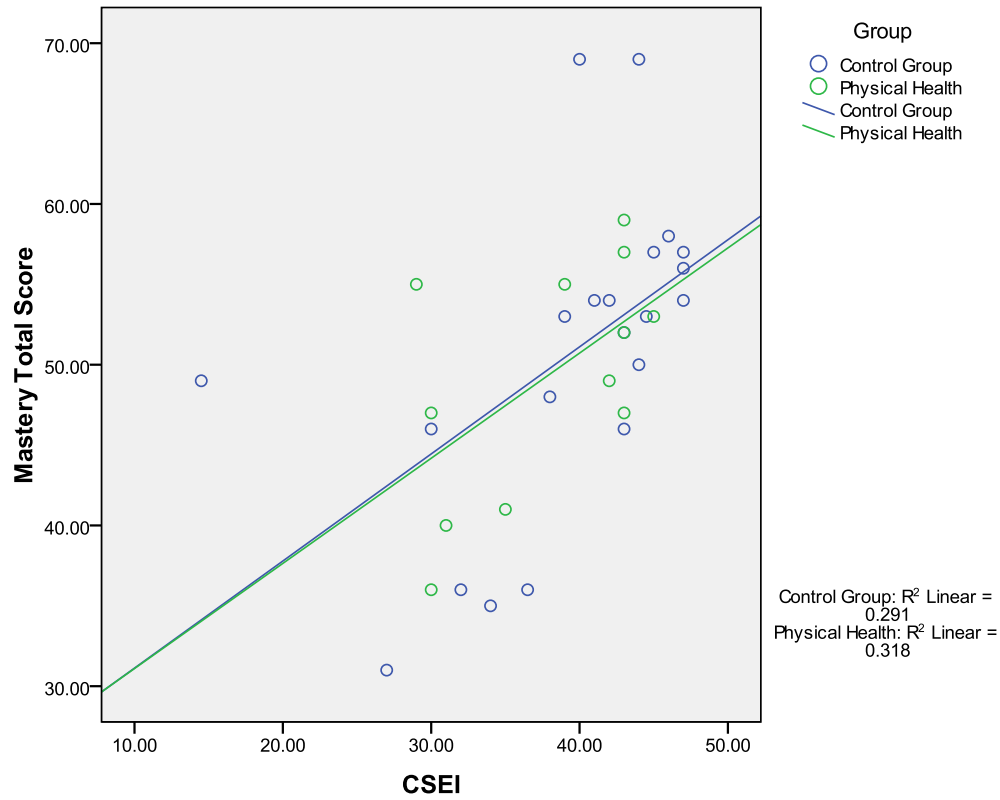
Dr Vinod Patel
DARE Director

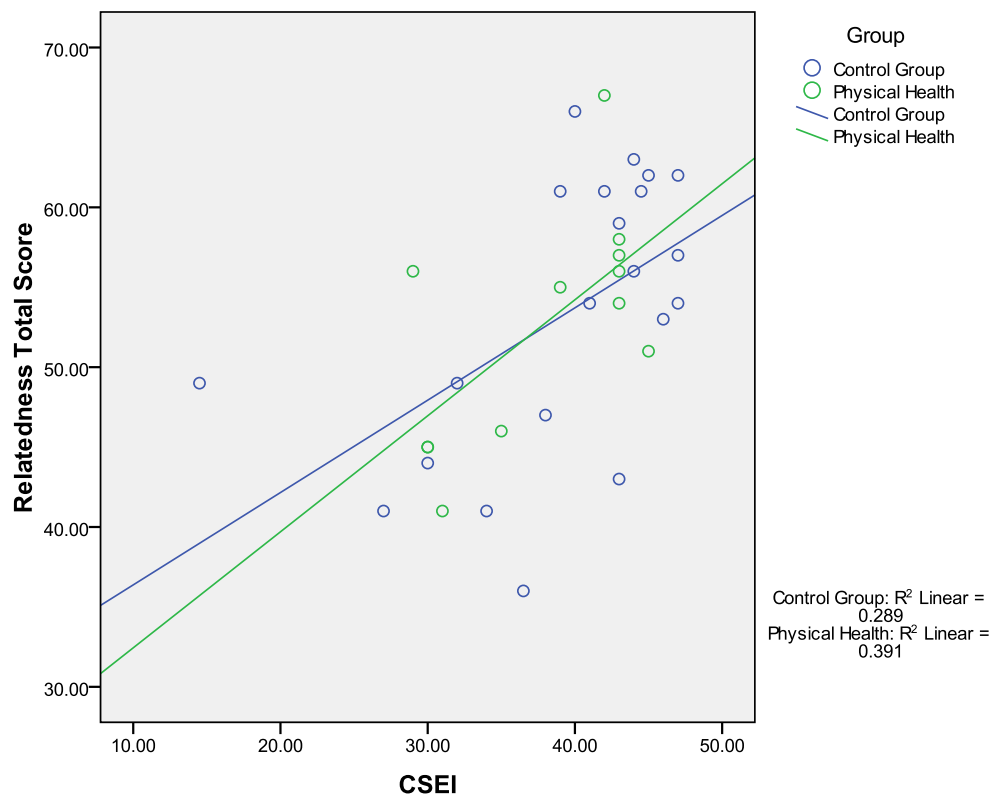
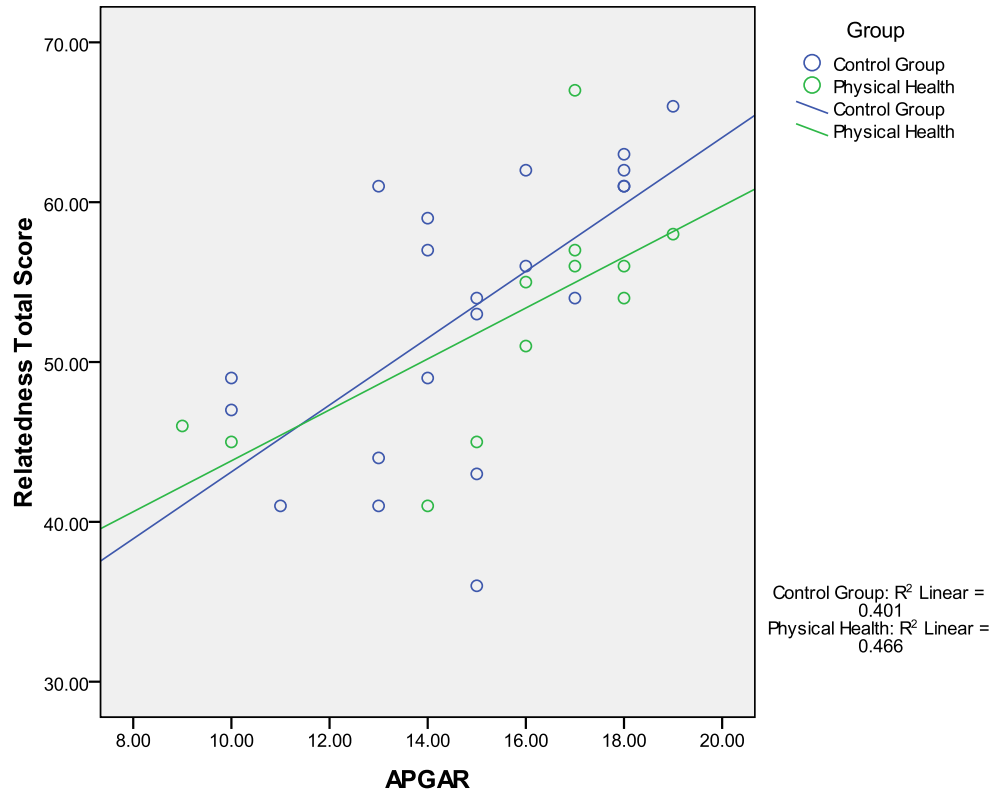


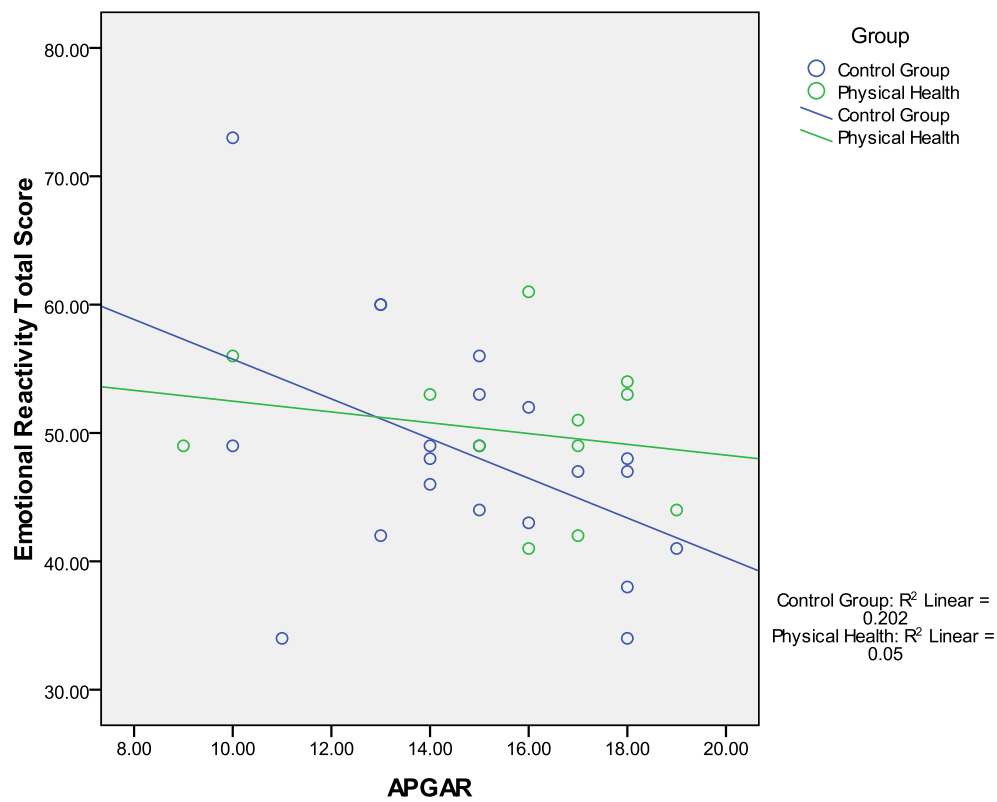
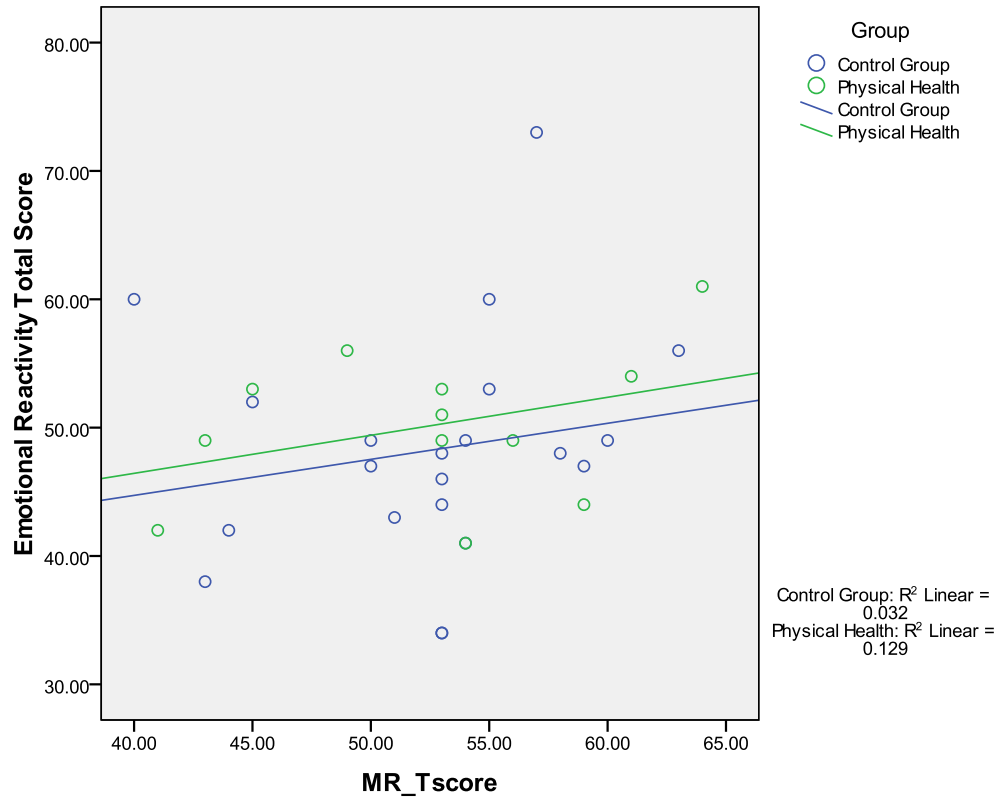


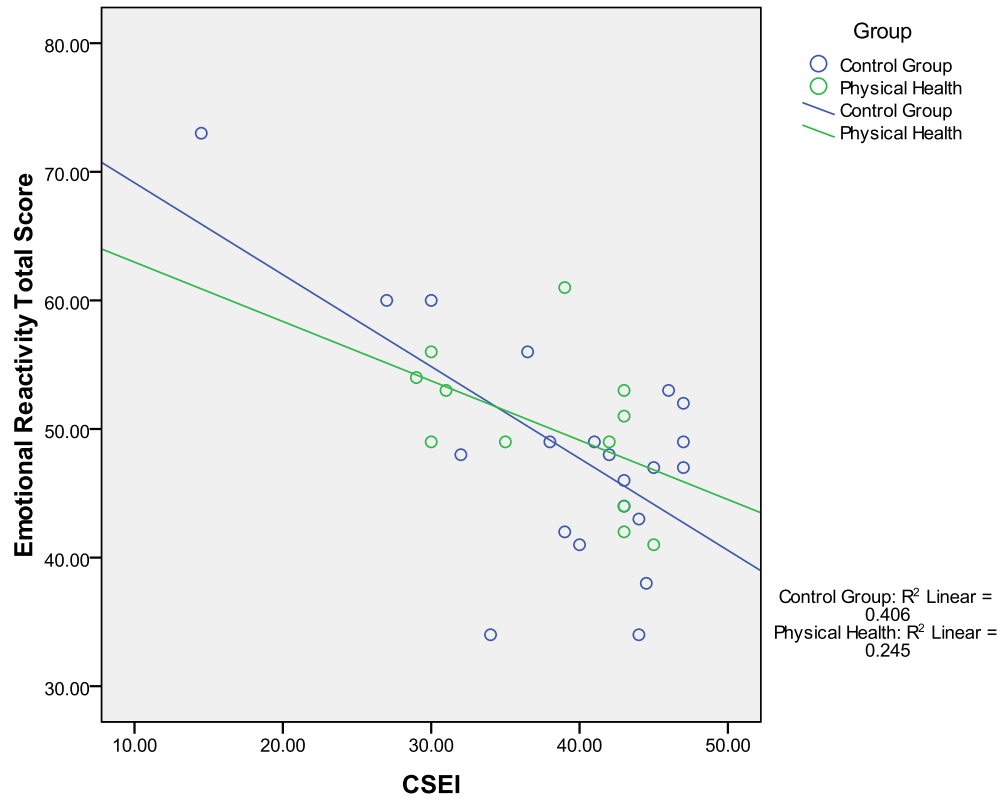












INSTRUCTION TO AUTHORS (Clinical Child Psychology and Psychiatry)

Peer review process. The Editor will screen manuscripts for their overall fit with the aims and scope of the journal. Those that fit will be further reviewed by two or more independent reviewers. Papers will be evaluated by the Editorial Board and refereed in terms of merit, readability and interest. Unsolicited manuscripts will not be returned to the author.

Consent and confidentiality. Disclosure should be kept to a minimum necessary to fulfil the objective of the article. All identifying details should be omitted if they are not essential. The material should be further disguised so that none of the individuals involved could recognise themselves. Some material that is particularly distinctive should be omitted or aggregated. Patient consent to publish should be sought whenever possible, even if the data are anonymized. In case reports where ensuring anonymity is impossible, written consent must be obtained from the clients described, or their legal representative, and submitted with the manuscript. Contributors to the journal should be aware of the risk of complaint by individuals in respect of defamation and breach of confidentiality. If there is concern, then authors should seek legal advice. Authors submitting research reports should confirm that approval from the appropriate ethical committee has been granted.

Conflict of interest Authors should make clear if the research has been funded, by whom, and the role of the funders in the project.

Complaints The Editor will respond promptly to complaints. Cogent criticism from readers will be taken seriously and considered for publication. Authors of criticized material will be given the opportunity to have a response published.

Submission of MSS. Articles should be submitted by email initially for the Editor's screening in the format outlined below.

Format of MSS. Manuscripts should be **typed in double spacing throughout**. All pages should be numbered. Each manuscript should contain the following, in the correct order.

(a) Title page to include the title of the paper, full name of each author, current professional position and work context, and indicators of which author will be responsible for correspondence. A word count should also be included.

(b) Abstract: should not exceed 200 words (150 for preference); up to **5 key words to be listed alphabetically on the same page**. This page should carry the title of the paper but not the author name(s).

(c) Main text: not usually to exceed 7500 words and to be clearly organized, with a clear hierarchy of headings and subheadings (3 weights maximum).

(d) References: Citation of references follows APA (American Psychological Association) style. References cited in the text should read thus: Brown (1955, pp. 63-64); (Brown, 1995,

pp. 63-64; Green & Brown, 1992, p. 102, Table 3). The letters a, b, c, etc., should distinguish citations of different works by the same author in the same year (Black, 1989a, 1989b).

All references cited in the text should appear in an alphabetical list, after the Notes section.

(e) Figures, tables, etc.: should be numbered consecutively, carry descriptive captions and be clearly cited in the text. Keep them separate from the text itself, but indicate an approximate location on the relevant text page. Line diagrams should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

(f) Author biographies: On a separate sheet provide a one-paragraph biobibliographical note for each author - up to 100 words for a single author, but none to exceed 65 words in a multi-authored paper.

Style. Use a clear and readable style, avoiding jargon. If technical terms must be included, define them when first used. Use plurals rather than he/she, (s)he, his or hers: 'If a child is unhappy, he or she. . . ' is much better expressed as 'When children are unhappy, they. . . '.

Spelling. British or American spellings may be used ('z' versions of British spellings preferred to 's' versions, as given in the Oxford English Dictionary).

Punctuation. Use single quotation marks, with double inside single. Present dates in the form 9 May 1996. Do not use points in abbreviations, contractions or acronyms (e.g. DC, USA, DR, UNESCO).

Covering letter. Attach to every submission a letter confirming that all authors have agreed to the submission and that the article is not currently being considered for publication by any other journal. The name, address, telephone and fax number and email address of the corresponding author should always be clearly indicated.

• **Instructions for Authors**

Journal of Child and Family Studies

General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication. The research described in the manuscripts should be consistent with generally accepted standards of ethical practice. The anonymity of subjects and participants must be protected and identifying information omitted from the manuscript.

• **Manuscript Style**

All manuscripts should be formatted to print out double-spaced at standard 8" x 11" paper dimensions, using a 10 pt. font size and a default typeface (recommended fonts are Times, Times New Roman, Calibri and Arial). Set all margins at one inch, and do not justify the right margin. Double-space the entire manuscript, including title page, abstract, list of references, tables, and figure captions. After the title page, number pages consecutively throughout including the reference pages, tables, and figure legends.

The Journal encourages the publication of research that is virtually jargon-free and easy to read. Thus, a personalized manuscript, written in active tense, is preferred. For example, "This study examined . . ." could be stated as, "We examined . . ." The Journal encourages a conversational rather than an impersonal tone in the manuscripts. Hypotheses should be written as a part of the last paragraph of the Introduction and not in bullet form. All reference to the study being reported should be consolidated in the last (or, if necessary, the last and penultimate) paragraph of the Introduction and not scattered throughout the introductory section.

Title Page

A title page is to be provided and should include: (1) the title (maximum of 15 words); (2) full names of the authors (without degree), with a bullet between the names of the authors; (3) brief running head; and, at the bottom of the title page, (4) the corresponding author's initials and last name (without degree), affiliation, mailing address, and e-mail address. The initials and last name of all authors should be listed as well. All authors from the same institution should be listed together, with a bullet separating the names. For all, but the corresponding author, list the affiliation, city and state only.

Abstract

The abstract should be between 200 and 250 words. It should be concise and complete in itself without reference to the body of the paper. In addition to a general statement about the field of research as the first sentence, abstracts of experimental/research papers should contain a brief summary of the paper's purpose, method (design of the study, main outcome measures, and age

range of subjects), results (major findings), and clinical significance. Abstracts of review papers should include a general statement about research area being reviewed as the first sentence, it should contain a brief summary of the review's purpose, method (data sources, study selection process), results (methods of data synthesis and key findings), and conclusions (summary statement of what is known, including potential applications and research needs). Do not use sub-headings and do not cite data or references in the abstract.

Key Words

A list of 5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

Text

Text should begin on the second numbered page. Authors are advised to spell out all abbreviations (other than units of measure) the first time they are used. Do not use footnotes to the text. When using direct quotations from another publication, cite the page number for the quotation in the text, immediately after the quotation. When reporting statistically significant results, include the statistical test used, the value of the test statistic, degrees of freedom, and p values. In the discussion include an evaluation of implications (clinical, policy, training or otherwise) of the study when appropriate. Also, discuss limitations in study design or execution that may limit interpretation of the data and generalizability of the findings. Do not use any sub-headings in the Introduction or Discussion sections.

Footnotes

No footnotes are to be used.

References Cited Within the Text

Cite references in alphabetical order within the text.

References

The accuracy of the references is the responsibility of the authors.

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

- last names and initials of all authors,

year published (in brackets)

title of article

name of publication

volume number

and inclusive pages

Do not include issue numbers of journals unless each issue begins with page 1. For book chapters, include volume number (if applicable) and page numbers, as shown below.

Consult the Publication Manual of the American Psychological Association, 6th Edition (Chapter 7) for formatting references. The style and punctuation of the references should conform to strict APA style – illustrated by the following examples:

• Journal Article:

Roelofs, J., Meesters, C., & Muris, P. (2008). Correlates of self-reported attachment (in)security in children: The role of parental romantic attachment status and rearing behaviors. *Journal of Child and Family Studies*, 17, 555-566.

Book:

McBee, L. (2008). *Mindfulness-based elder care: A CAM model for frail elders and their caregivers*. New York: Springer.

Book Chapter:

Singh, N.N., Winton, A.S.W., Singh, J., McAleavey, K., Wahler, R.G., & Sabaawi, M. (2006). Mindfulness-based caregiving and support. In J.K. Luiselli (Ed.), *Antecedent assessment and intervention: Supporting children and adults with developmental disabilities in community settings* (pp. 269-290). Baltimore, MD: Paul H. Brookes.

Tables

Tables follow the Reference section. Create tables using the table creation and editing feature of your word processing software (e.g., Word) instead of spreadsheet programs. Tables that are a single column are actually lists and should be included in the text as such. Number tables consecutively using Arabic numerals in order of appearance in the text. Cite each table in the text and note approximately where it should be placed. Type each table on a separate page with the title and legend included. Double-space the table and any footnotes to it. Set each separate entry in a single table cell. Do not use underlining. Properly align numbers, both horizontally and vertically. Use brief headings for columns. If abbreviations are necessary, define them in a key at the bottom of the table. Keep footnotes to a minimum; if necessary, use superscript letters to denote them.

Figures

Figures follow the tables. Figures must be submitted in electronic form. Figures and illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals.